DOCUMENT RESUME

ED 308 986 PS 018 193

TITLE	Reaching Out: A Directory of National Organizations Related to Maternal and Child Health.
INSTITUTION	National Center for Education in Maternal and Child Health, Washington, DC.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE	Mar 89
GRANT	OMCH-MCJ-117006-01-0
NOTE	126p.
PUB TYPE	Reference Materials - Directories/Catalogs (132)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	Adolescents; Children; *Health Materials; Information Sources; *Medical Associations; Mothers; *National Organizations; Public Health; *Resource Materials
IDENTIFIERS	*Child Health; Health Resources Information; *Maternal Health

ABSTRACT

This directory lists addresses, phone numbers, and contact persons for over 450 national organizations with a maternal and child health focus. The directory is divided into two sections. The first lists national organizations by subject area. These organizations provide a variety of services and activities, such as publication of educational materials, dissemination of general information, referrals, and assistance to health professionals and consumers in meeting their needs. Organizations listed in this section focus on: (1) pregnancy and childbirth; (2) infant health; (3) child health; (4) adolescent health; (5) school health; (6) women's health; (7) nutrition; (8) genetic services; (9) chronic illness and disability; (10) special health care needs; (11) public health programs and services; (12) health care providers. The second section lists self-help clearinghouses which collect and disseminate information about local self-help groups and assist in the formation of new groups. This section is arranged alphabetically by state. Two indexes are included; the first is a detailed subject index and the second is an alphabetical list of all organizations covered. (RJC)

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REACHING OUT:

A Directory of National Organizations Related to Maternal and Child Health

PS 018193

NCEMCH
National Center for Education in Maternal and Child Health

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REACHING OUT:

A Directory of National Organizations Related to Maternal and Child Health

March 1989

NCEMCH
National Center for Education in Maternal and Child Health

National Center for Education in Maternal and Child Health
(NCEMCH)
38th & R Streets, N.W.
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NCEMCH provides information services, educational materials, and technical assistance to organizations, agencies, and individuals with maternal and child health interests.

The Center was established in 1982 at Georgetown University, within the Department of Obstetrics and Gynecology. NCEMCH is primarily funded by the U.S. Department of Health and Human Services through its Bureau of Maternal and Child Health and Resources Development.

THIS PUBLICATION WAS MADE POSSIBLE THROUGH GRANT NUMBER MCJ-117006-01-0 FROM THE OFFICE OF MATERNAL AND CHILD HEALTH, BUREAU OF MATERNAL AND CHILD HEALTH AND RESOURCES DEVELOPMENT, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES.

Table of Contents

Foreword *ix*

PART I: NATIONAL ORGANIZATIONS

PREGNANCY AND CHILDBIRTH **1**
General 1
Birth Settings 1
Cesarean Birth 2
Childbirth Preparation 2
Multiple Birth 3
Perinatal Care 4
Physical Fitness 4
Pregnancy Loss 4
Prenatal Care 5
Reproductive Hazards 6
Reproductive Technologies 6

INFANT HEALTH **7**
General 7
Breastfeeding 7
Early Intervention 7
Infant Mortality 7
Prematurity 8
Sudden Infant Death Syndrome 8

CHILD HEALTH **10**
Accident/Injury Prevention 10
Adoption 11
Advocacy 12
Child Abuse/Neglect 12
Child Care 13
Dental Health 13
Development/Education 14
Family Support 15
Pediatrics 16
Reye Syndrome 17

ADOLESCENT HEALTH **18**
General 18
Adolescent Medicine 18
Adolescent Pregnancy 19
Behavioral Problems 20
Suicide Prevention 20

SCHOOL HEALTH **21**

WOMEN'S HEALTH	**24**
General	24
Family Conflict	24
Family Planning	24
Reproductive Health	25
NUTRITION	**27**
GENETIC SERVICES	**28**
CHRONIC ILLNESS AND DISABILITY	**29**
General	29
Auditory Disorders	29
Deafness/Hearing Impairment	29
Speech and Hearing	30
Tinnitus	31
Cancer	31
General	31
Brain Tumor	32
Breast Cancer	32
Childhood Cancer	32
Gastrointestinal Polyposis	32
Leukemia	33
Cardiovascular Disorders	33
Chromosomal Abnormalities	33
Cri-du-Chat Syndrome	33
Down Syndrome	34
Fragile X Syndrome	34
Monosomy 9p	35
Prader Willi Syndrome	35
Trisomy 18/Trisomy 13	35
Turner Syndrome	35
Connective Tissue Disorders	35
Ehlers-Danlos Syndrome	35
Fibrodysplasia Ossificans Progressiva	36
Marfan Syndrome	36
Pseudoxanthoma Elasticum	36
Craniofacial Disorders	36
General	36
Cleft Lip/Palate	37
Developmental Disabilities	38
General	38
Autism	38
Cerebral Palsy	38
Cockayne Syndrome	39
Cornelia de Lange Syndrome	39
Hyperactivity	39

Klippel-Trenaunay-Weber Syndrome 39
Laurence-Moon-Biedl Syndrome 39
Learning Disabilities 40
Mental Retardation 40
Progeria 41
Rubinstein-Taybi Syndrome 41
Smith-Lemli-Opitz Syndrome 41
Eating Disorders 42
Gastrointestinal Disorders 42
General 42
Celiac Disease 42
Ileitis/Colitis 43
Liver Disorders 43
Genitourinary Disorders 43
Hematologic Disorders 43
Fanconi Anemia 43
Hemochromatosis/Iron Overload Disorders 44
Hemophilia 44
Hereditary Hemorrhagic Telangiectasia 44
Histiocytosis-X 45
Sickle Cell Disease 45
Thalassemia 45
Thrombocytopenia Absent Radius Syndrome 45
Immunologic Disorders 46
Chronic Fatigue Immune Dysfunction 46
Immune Deficiency 46
Sjogren Syndrome 46
Systemic Lupus Erythematosus 46
Infectious Diseases 47
Acquired Immune Deficiency Syndrome 47
Kidney Disorders 47
Mental Health 47
Metabolic Disorders 48
Albinism/Hypopigmentation 48
Cystic Fibrosis 49
Cystinosis 49
Diabetes 49
Dysautonomia 49
Galactosemia 50
Gaucher Disease 50
Glycogen Storage Disease 50
Leukodystrophy 50
Lowe Syndrome 50
Malignant Hyperthermia 51
Maple Syrup Urine Disease 51
Mucolipidoses/Mucopolysaccharidoses 51
Neuro-Metabolic Disorders 51
Organic Acidemia 52
Porphyria 52
Tay-Sachs Disease 52
Williams Syndrome 52

Wilson Disease 53
Musculoskeletal Disorders 53
General 53
Arthritis 53
Arthrogryposis Multiplex Congenita 53
Freeman-Sheldon Syndrome 54
Osteogenesis Imperfecta 54
Paget Disease 54
Scoliosis 54
Neurologic Disorders 55
General 55
Acoustic Neuroma 55
Alzheimer Disease 55
Angelman Syndrome 55
Ataxia 55
Batten Disease 56
Epilepsy 56
Guillain-Barre´ Syndrome 56
Head Injury 57
Huntington Disease 57
Hydrocephalus 57
Joseph Diseases 58
Narcolepsy 58
Neurofibromatosis 58
Parkinson Disease 58
Reflex Sympathetic Dystrophy Syndrome 59
Rett Syndrome 59
Spasmodic Torticollis 59
Spina Bifida 60
Sturge-Weber Syndrome 60
Tourette Syndrome 60
Tuberous Sclerosis 60
Neuromuscular Disorders 61
Amyotrophic Lateral Sclerosis 61
Charcot-Marie-Tooth Disease/Peroneal Muscular Atrophy 61
Dystonia 61
Multiple Sclerosis 62
Muscular Dystrophy 62
Myasthenia Gravis 62
Myoclonus 62
Spinal Muscular Atrophy 62
Respiratory Disorders 63
General 63
Allergy/Asthma 63
Short Stature 64

Skin Disorders 64
Alopecia Areata 64
Congenital Port Wine Stain 64
Ectodermal Dysplasias 64
Epidermolysis Bullosa 65
Ichthyosis 65
Scleroderma 65
Xeroderma Pigmentosum 65
Substance Abuse 66
Visual Disorders 67
Blindness/Visual Impairment 67
Cataracts 68
Retinal Degeneration 69

SPECIAL HEALTH CARE NEEDS 70
General 70
Adoption 70
Advocacy 70
Dental Health for the Disabled 71
Family-Centered Care 71
Recreation 73
Rehabilitation 74
Sexuality 75
Special Education 75

PUBLIC HEALTH PROGRAMS AND SERVICES 76
General 76
Community Health 76
Health Care Financing 77
Health Policy 78
Health Promotion 79
Native Americans 80
State Maternal and Child Health Programs 80

HEALTH CARE PROVIDERS 81

PART II: SELF-HELP CLEARINGHOUSES 87

United States 88
Canada 98

SUBJECT INDEX 99

ORGANIZATION INDEX 109

Foreword

Reaching Out: A Directory of National Organizations Related to Maternal and Child Health has been compiled by the National Center for Education in Maternal and Child Health (NCEMCH) to provide a reference to national organizations with a maternal and child health focus. Information for this third edition was obtained by communicating with organizations in the United States and Canada.

Part One of *Reaching Out* lists national organizations by subject area. These organizations provide a variety of services and activities, including publishing educational materials, disseminating general information, making referrals, and furnishing support to assist the health professional or the health care consumer in meeting a specific need.

Part Two lists self-help clearinghouses. These organizations collect and disseminate information about local self-help groups and assist in the formation of new groups. This section is arranged alphabetically by state.

Two indexes are included. The first is a detailed subject index. The second is an alphabetical list of all organizations.

The National Center for Education in Maternal and Child Health would like to thank all the organizations that provided information for this directory. *Reaching Out* will be updated and expanded for future editions; suggestions and changes may be directed to:

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(202) 638-0026
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Cesarean Support, Education, and Concern (C/SEC)

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Beth Shearer and Norma Shulman,
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American Society for Prophylaxis in Obstetrics (ASPO/Lamaze)

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Patrice Hassid, Registrar

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Albuquerque, New Mexico 87112-4640

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(415) 644-0863
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Providence, Rhode Island 02940-9487

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(800) 433-5523
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Association for Recognizing the Life of Stillborns (ARLS)

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La Crosse-Lutheran Hospital
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LaCrosse, Wisconsin 54601

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American Academy of Pediatrics (AAP)

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National Commission to Prevent Infant Mortality

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Sudden Infant Death Syndrome

Association of SIDS Program Professionals

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Center for Youth Services

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Adolescent Pregnancy

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Chronic Illness and Disability

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March of Dimes Birth Defects Foundation

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National Foundation for Jewish Genetic Diseases, Inc. (NFJGD)

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National Organization for Rare Disorders, Inc. (NORD)

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Auditory Disorders

DEAFNESS/HEARING IMPAIRMENT

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American Speech-Language-Hearing Association (ASHA)

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TINNITUS

American Tinnitus Association

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Cancer

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American Cancer Society

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National Cancer Care Foundation (NCCF)

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BRAIN TUMOR

Association for Brain Tumor Research (ABTR)

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BREAST CANCER

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CHILDHOOD CANCER

Candlelighters Childhood Cancer Foundation

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GASTROINTESTINAL POLYPOSIS

Familial Polyposis Registry

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Leukemia Society of America, Inc.

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Cardiovascular Disorders

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Chromosomal Abnormalities

CRI-DU-CHAT SYNDROME

5p- Society

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FRAGILE X SYNDROME

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MONOSOMY 9p

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PRADER-WILLI SYNDROME

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TRISOMY 18/TRISOMY 13

Support Organization for Trisomy 18/13 and Other Related Dsorders (SOFT 18/13)

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TURNER SYNDROME

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Connective Tissue Disorders

EHLERS-DANLOS SYNDROME

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CLEFT LIP/PALATE

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Developmental Disabilities

GENERAL

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COCKAYNE SYNDROME

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CORNELIA de LANGE SYNDROME

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HYPERACTIVITY

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KLIPPEL-TRENAUNAY-WEBER (K-T) SYNDROME

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211 East 300 South Street
Suite 212
Salt Lake City, Utah 84111

(801) 328-1575
Dr. Ernest H. Dean, President

National Association of State Mental Retardation Program Directors

113 Oronoco Street
Alexandria, Virginia 22314

(703) 683-4202
Robert M. Gettings, Executive Director
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National Association for the Dually Diagnosed (NADD)

(Mental Illness/Mental Retardation)

110 Prince Street
Kingston, New York 12401

(914) 331-4336
Robert J. Fletcher, A.C.S.W., Executive Director

PROGERIA

Progeria International Registry

North Shore University
Division of Human Genetics
300 Community Drive
Manhasset, New York 11030

(516) 562-4610
W. Ted Brown, M.D., Ph.D., Executive Director

RUBINSTEIN-TAYBI SYNDROME

Rubinstein-Taybi Syndrome (RTS) Parent Group

414 East Kansas
Smith Center, Kansas 66967

(913) 282-6237
Contact: Lorrie or Garry Baxter

SMITH-LEMLI-OPITZ SYNDROME

Smith-Lemli-Opitz Syndrome Support Group

Five Hampton Court
Newark, Delaware 19703

(302) 834-4157
Contact: Carol Lolor

Eating Disorders

American Anorexia/Bulimia Association, Inc. (AABA)

133 Cedar Lane
Teaneck, New Jersey 07666

(201) 836-1800
Linda Rothenbert, M.S.W., Executive Director

National Association of Anorexia Nervosa and Associated Disorders, Inc. (ANAD)

P.O. Box Seven
Highland Park, Illinois 60035

(312) 831-3438
Vivian Meehan, President
Contact: Christopher Athas, Vice President or Dawn M. Ries, Administrator

Gastrointestinal Disorders

GENERAL

American Digestive Disease Society (ADDS)

7220 Wisconsin Avenue
Bethesda, Maryland 20814

(301) 223-0179
Marlin I. Hassner, Executive Director

CELIAC DISEASE

American Celiac Society

45 Gifford Avenue
Jersey City, New Jersey 07304

(201) 432-1207
Anita Garrow, Executive Director

Celiac Sprue Association/United States of America, Inc. (CSA/USA)

2313 Rocklyn Drive
Suite One
Des Moines, Iowa 50322

(515) 270-9689
Contact: Tracey Mohns

Gluten Intolerance Group of North America (GIG)

P.O. Box 23053
Seattle, Washington 98102-0353

(206) 325-6980
Elaine I. Hartsook, Ph.D., R.D., Executive Director

ILEITIS/COLITIS

National Foundation for Ileitis and Colitis, Inc. (NFIC)

444 Park Avenue South
New York, New York 10016-7374

(212) 685-3440
George Theobald, Jr., Executive Director
Contact: Terry Jennings, Director of Communications

LIVER DISORDERS

American Liver Foundation (ALF)

998 Pompton Avenue
Cedar Grove, New Jersey 07009

(201) 857-2626
Thelma King Thiel, President
Contact: Fran Weiss, Public Relations Director

Children's Liver Foundation, Inc. (CLF)

76 South Orange Avenue
Suite 202
South Orange, New Jersey 07079

(201) 761-1111
Maxine Turon, President

Genitourinary Disorders

Interstitial Cystitis Association, Inc.

P.O. Box 1553
Madison Square Station
New York, New York 10159

(212) 674-1454
Vicki Ratner, President

Hematalogic Disorders

FANCONI ANEMIA

Fanconi Anemia Support Group

2875 Baker Boulevard
Eugene, Oregon 97403

(503) 686-0434
David B. Frohnmayer, Executive Director
Contact: Lynn or David Frohnmayer

HEMOCHROMATOSIS/ IRON OVERLOAD DISEASES

Hemochromatosis Research Foundation, Inc.

P.O. Box 8569
Albany, New York 12208

(518) 489-0972
Margaret A. Krikker, M.D., President

Iron Overload Diseases Association, Inc. (IOD)

224 Datura Street
Suite 311
West Palm Beach, Florida 33401

(305) 659-5616
(305) 659-5677
Roberta Crawford, Executive Director

HEMOPHILIA

Canadian Hemophilia Society

100 King Street West
Suite 210
Hamilton, Ontario L8P 1A2
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(416) 523-6414
Robert Shearer, Executive Director

National Hemophilia Foundation (NHF)

The Soho Building
110 Greene Street
Suite 406
New York, New York 10012

(212) 219-8180
Alan P. Brownstein, Executive Director

HEREDITARY HEMORRHAGIC TELANGIECTASIA (Osler-Weber-Rendu Syndrome)

Hereditary Hemorrhagic Telangiectasia Foundation, Inc. (HHT)

Biochemistry Department
University of Massachusetts
Amherst, Massachusetts 01003

(413) 545-2048 (Massachusetts)
(415) 328-4854 (California)
Bruce Jacobson, Ph.D., Executive Director
Contact: Sharon Victor (Palo Alto, California)

HISTIOCYTOSIS-X

Histiocytosis-X Association of America, Inc.

609 New York Road
Glassboro, New Jersey 08028

(609) 881-4911
Jeffrey M. Toughill, Executive Director

SICKLE CELL DISEASE

National Association for Sickle Cell Disease, Inc. (NASCD)

4221 Wilshire Boulevard
Suite 360
Los Angeles, California 90010-3503

(800) 321-8453
(213) 936-7205
Dorothye H. Boswell, Executive Director

THALASSEMIA

Cooley's Anemia Foundation, Inc.

105 East 22nd Street
New York, New York 10010

(212) 598-0911
Teresa G. Piropato, Executive Director

Thalassemia Action Group

105 East 22nd Street
New York, New York 10010

(212) 598-0911
Ralph Cazzetta, President

THROMBOCYTOPENIA ABSENT RADIUS SYNDROME

Thrombocytopenia Absent Radius Association (TARSA)

312 Sherwood Drive, R.D. One
Linwood, New Jersey 08221

(609) 927-0418
Edward and Sandra Purinton, Executive Directors

Immunologic Disorders

IMMUNE DEFICIENCY

Chronic Fatigue Immune Dysfunction Society

P.O. Box 23018
Portland, Oregon 97223

(503) 684-5261
Gidget Faubion, Executive Director

Immune Deficiency Foundation

P.O. Box 586
Columbia, Maryland 21045

(301) 461-3127
Marcia Boyle, President

SJOGREN SYNDROME

Sjogren's Syndrome Foundation, Inc.

29 Gateway Drive
Great Neck, New York 11021

(516) 487-2243
Elaine K. Harris, President

SYSTEMIC LUPUS ERYTHEMATOSUS

The American Lupus Society

23751 Madison Street
Torrance, California 90505

(213) 373-1335
Milton H. Abram II, President
Contact: Charlean Wakefield

Lupus Foundation of America (LFA)

1717 Massachusetts Avenue, N.W.
Suite 203
Washington, D.C. 20036

(202) 328-4550
James E. Lewis, National President

Infectious Diseases

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Foundation for Children with AIDS

77 B Warren Street
Brighton, Massachusetts 02135

(617) 783-7300
Geneva Woodruff, Executive Director

Kidney Disorders

National Kidney Foundation, Inc.

2 Park Avenue
Suite 908
New York, New York 10016

(212) 889-2210
John Davis, Executive Director
Contact: Gigi Politoski, Public Information Director

National Association of Patients on Hemodialysis and Transplantation, Inc. (NAPHT)

211 East 43rd Street
New York, New York 10017

(212) 867-4486
Stuart Kaufer, Executive Director

PKR (Polycystic Kidney Research) Foundation

922 Walnut Street
Kansas City, Missouri 64106

(816) 421-1869
Jean G. Bacon, Executive Director
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Mental Health

American Mental Health Fund

3299 Woodburn Road
Suite 335
Annandale, Virginia 22003

(703) 573-2200
David George, Executive Director

American Orthopsychiatric Association

19 West 44th Street
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New York, New York 10036

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Contact: Faith Lamb Parker, Ph.D.

Depression and Related Affective Disorders Association, Inc. (DRADA)

The Johns Hopkins Hospital
Meyer 4-181
601 North Wolfe Street
Baltimore, Maryland 21205

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(301) 955-4647, 3246
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National Association for the Dually Diagnosed (NADD)

(Mental Illness/Mental Retardation)

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National Mental Health Association (NMHA)

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Alexandria, Virginia 22314

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Contact: Bonnie F. O'Neill, Manager, Communications

Speaking for Our Selves (S4OS)

(Multiple Personalities)

P.O. Box 4830
Long Beach, California 90804

(213) 438-7467
Rachel A., President

Metabolic Disorders

ALBINISM/HYPOPIGMENTATION

National Organization for Albinism and Hypopigmentation (NOAH)

1500 Locust Street, Suite 1811
Philadelphia, Pennsylvania 19102-4316

(215) 471-2278
(215) 471-2265
Janice L. Knuth, A.C.S.W., President

CYSTIC FIBROSIS

Cystic Fibrosis Foundation

6931 Arlington Road
Bethesda, Maryland 20814

(800) FIGHT CF
(301) 951-4422
Robert K. Dresing, President
Contact: Mark Hansan, Executive Assistant to the President

CYSTINOSIS

Cystinosis Foundation, Inc.

477 15th Street
Suite 200
Oakland, California 94612

(415) 834-7897
Jean Hotz, President

DIABETES

American Diabetes Association, Inc.

1660 Duke Street
Alexandria, Virginia 22314

(703) 549-1500
Robert S. Bolan, Ph.D., Executive Vice President

Juvenile Diabetes Foundation International

432 Park Avenue South
16th Floor
New York, New York 10016

(212) 889-7575
Gloria Pennington, Executive Director
Contact: Mary Kelley

DYSAUTONOMIA

Dysautonomia Foundation, Inc.

370 Lexington Avenue
New York, New York 10017

(212) 889-5222
Lenore F. Roseman, Executive Director

GALACTOSEMIA

Parents of Galactosemic Children, Inc.

One Ash Court
New City, New York 10956

(914) 638-3650
Contact: Linda Manis

GAUCHER DISEASE

National Gaucher Foundation, Inc.

1424 K Street, N.W.
Fourth Floor
Washington, D.C. 20005

(202) 393-2777
Karen Cohen, Executive Director

GLYCOGEN STORAGE DISEASE

Association for Glycogen Storage Disease

Box 896
Durant, Iowa 52747

(319) 785-6038
Hollie Arp, President

LEUKODYSTROPHY

United Leukodystrophy Foundation, Inc. (ULF)

2304 Highland Drive
Sycamore, Illinois 60178

(815) 895-3211
Ron and Paula Brazeal, Co-Presidents

LOWE SYNDROME

Lowe's Syndrome Association, Inc.

222 Lincoln Street
West Lafayette, Indiana 47906

(317) 743-3634
Kaye McSpadden, President

MALIGNANT HYPERTHERMIA

Malignant Hyperthermia Association of the United States (MHAUS)

P.O. Box 3231
Darien, Connecticut 06820

(203) 655-3007
Suellen Gallamore, Executive Director

MAPLE SYRUP URINE DISEASE

Maple Syrup Urine Disease (MSUD) Family Support Group

RR #2, Box 24-A
Flemingsburg, Kentucky 41041

(606) 849-4679
Joyce Brubacher, Executive Director
Contact: Peter Shaffer

MUCOLIPIDOSES/MUCOPOLYSACCHARIDOSES

ML (Mucolipidosis) IV Foundation

Six Concord Drive
Monsey, New York 10952

(914) 425-0639
Lynn Goldblatt, Executive Director

National MPS Society

(Mucopolysaccharidoses and Mucolipidoses)

17 Kraemer Street
Hicksville, New York 11801

(516) 931-6338
Marie Capobianco, President

Zain Hansen M.P.S. Foundation

(Mucopolysaccharidoses)

1200 Fernwood Drive
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Arcata, California 95521

(707) 822-5421
Carl Zichella, President
Contact: LeAnna Carson-Hansen

NEURO-METABOLIC DISORDERS

Association of Neuro-Metabolic Disorders

5223 Brookfield Lane
Sylvania, Ohio 43560

(419) 885-1497
Contact: Cheryl Volk

ORGANIC ACIDEMIA

Organic Acidemia Association, Inc.

1532 South 87th Street
Kansas City, Kansas 66111

(913) 422-7080
Lorie Asten, Coordinator

PORPHYRIA

American Porphyria Foundation

P.O. Box 11163
Montgomery, Alabama 36111

(205) 265-2200
Desiree Dodson, Executive Director

TAY-SACHS DISEASE

National Tay-Sachs and Allied Diseases Association (NTSAD)

(Allied Diseases: Gaucher Disease, Krabbe Disease, Niemann-Pick Disease, Sandhoff Disease)

385 Elliot Street
Newton, Massachusetts 02164

(617) 964-5508
Dale I. Carre, Executive Director

WILLIAMS SYNDROME

Canadian Association for Williams Syndrome (CAWS)

3806 Garden Grove Drive
Burnaby, British Columbia V5G 4A7
Canada

(604) 433-8979
Contact: Patrice Pratt

Williams Syndrome Association (WSA)

P.O. Box 178373
San Diego, California 92117-0910

(713) 376-7072
Gordon Biescar, Executive Director
Contact: Kay Biescar, Administrative Assistant

WILSON DISEASE

Foundation for the Study of Wilson's Disease, Inc.

5447 Palisade Avenue
Bronx, New York 10471

(212) 430-2091
Contact: I. Herbert Scheinbert, M.D.

Wilson's Disease Association (Also Menkes Disease)

P.O. Box 75324
Washington, D.C. 20013

(703) 636-3014
(703) 636-3003
Carol A. Terry, Executive Director

Musculoskeletal Disorders

GENERAL

American Academy of Orthopaedic Surgeons

222 South Prospect Avenue
Park Ridge, Illinois 60068

(312) 823-7186
Thomas C. Nelson, Executive Director
Contact: Cindy Thomas

ARTHRITIS

Arthritis Foundation
American Juvenile Arthritis Organization (AJAO)

1314 Spring Street, N.W.
Atlanta, Georgia 30309

(404) 872-7100
Clifford Clarke, President
Contact: Linda Weatherbee, Vice President for AJAO and Special Projects

ARTHROGRYPOSIS MULTIPLEX CONGENITA

AVENUES (National Support Group for Arthrogryposis Multiplex Congenita)

P.O. Box 5192
Sonora, California 95379

(209) 928-3688
Mary Anne and Jim Schmidt, Executive Directors

FREEMAN-SHELDON SYNDROME

Freeman-Sheldon Parent Support Group

1459 East Maple Hills Drive
Bountiful, Utah 84010

(801) 298-3149
Joyce Dolcourt, Executive Director

OSTEOGENESIS IMPERFECTA

Osteogenesis Imperfecta Foundation, Inc. (OIF)

P.O. Box 14807
Tampa, Florida 34629-4807

(813) 855-7077
Rosalind James, President
Contact: Linda K. Phillips, Staff Assistant

Osteogenesis Imperfecta—National Capital Area (OI-NCA)

Box 941
1311 Delaware Avenue, S.W.
Washington, D.C. 20024

(202) 265-1614
Margaret Cauffield, Executive Director

PAGET DISEASE

Paget's Disease Foundation, Inc. (PDF)

165 Cadman Plaza East
Brooklyn, New York 11201

(718) 596-1043
Charlene Waldman, Executive Director

SCOLIOSIS

National Scoliosis Foundation, Inc.

93 Concord Avenue
P.O. Box 547
Belmont, Massachusetts 02178

(617) 489-0880
(617) 489-0888
Laura B. Gowen, Executive Director
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Scoliosis Association, Inc.

P.O. Box 51353
Raleigh, North Carolina 27609

(919) 846-2639
Barbara M. Shulman, President

Neurologic Disorders

GENERAL

American Academy of Neurology

2221 University Avenue, S.E.
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Minneapolis, Minnesota 55414

(612) 623-8115
Jan Kolehmainen, Executive Director
Contact: Richard P. Hames

ACOUSTIC NEUROMA

Acoustic Neuroma Association

P.O. Box 398
Carlisle, Pennsylvania 17013

(717) 249-4783
Virginia Fickel, President

ALZHEIMER DISEASE

Alzheimer's Disease and Related Disorders Association (ADRDA)

70 East Lake Street
Chicago, Illinois 60601

(800) 621-0379
(312) 853-3060
Edward Truschke, President

ANGELMAN SYNDROME

Angelman Research Group

Box J-296, JHMHC
Division of Genetics/Department of Pediatrics
University of Florida
Gainesville, Florida 32610-0296

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Jill Hendrickson, M.S., M.S.S.W., Coordinator

ATAXIA

Friedrich's Ataxia Group in America, Inc. (FAGA)

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Oakland, California 94611

(415) 655-0833
Raymond S. McCarthy, Executive Director
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National Ataxia Foundation

600 Twelve Oaks Center
15500 Wayzata Boulevard
Wayzata, Minnesota 55391

(612) 473-7666
Donna Gruetzmacher, Patient Services Director

BATTEN DISEASE

Batten's Disease Support and Research Association

6707 197th Street East
Spanaway, Washington 98387

(206) 847-2926
Judith A. Grant, President

Children's Brain Diseases Foundation

350 Parnassus Avenue
Suite 900
San Fransisco, California 94117

(415) 566-5402
J. Alfred Rider, M.D., Ph.D., Executive Director

EPILEPSY

Epilepsy Foundation of America (EFA)

4351 Garden City Drive
Landover, Maryland 20785

(301) 459-3700
William McLin, Executive Director
Contact: Marie Ormsby, Director of Information and Referral

GUILLAIN-BARRÉ SYNDROME

Guillain-Barré Syndrome Support Group International

P.O. Box 262
Wynnewood, Pennsylvania 19096

(215) 896-6855
Estelle and Robert Benson, Executive Directors
Contact: Estelle Benson

HEAD INJURY

National Head Injury Foundation, Inc.

333 Turnpike Road
Southboro, Massachusetts 01772

(617) 485-9950
Marilyn Price Spivack, Executive Director,
Contact: Janet Williams, M.S.W., Director of Clearinghouse

HUNTINGTON DISEASE

Hereditary Disease Foundation

606 Wilshire Boulevard
Suite 504
Santa Monica, California 90401-9990

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Scientific Adivsory Board
Contact: Nancy S. Wexler, Ph.D.

Huntington's Disease Society of America, Inc. (HDSA)

140 West 22nd Street
New York, New York 10011-2420

(212) 242-1968
Gary Wallach, Executive Director

Huntington Society of Canada

13 Water Street
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Cambridge, Ontario N1R 5T8
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(519) 622-1002
Ralah Walker, Director, Research and Patient/Family Services

HYDROCEPHALUS

National Hydrocephalus Foundation (NHF)

Route One River Road
Box 210 A
Joliet, Illinois 60436

(815) 467-6548
James A. Mazzetti, Executive Director

JOSEPH DISEASES

International Joseph Diseases Foundation, Inc. (IJDF)

P.O. Box 2550
Livermore, California 94550

Rose Marie J. Silva, Executive Director

NARCOLEPSY

American Narcolepsy Association

P.O. Box 1187
San Carlos, California 94070

(415) 591-7979
William P. Baird, Executive Director
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NEUROFIBROMATOSIS

National Neurofibromatosis Foundation, Inc.

141 Fifth Avenue
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New York, New York 10010

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(212) 460-8980
Peter Bellerman, Executive Director
Contact: Prissi Shapiro, Assistant Executive Director

PARKINSON DISEASE

American Parkinson Disease Association (APDA)

116 John Street
Suite 417
New York, New York 10038-9982

(800) 223-2732
(212) 732-9550
Frank L. Williams, Executive Director

National Parkinson Foundation, Inc. (NPF)

1501 Northwest Ninth Avenue-Bob Hope Road
Miami, Florida 33136-1494

(800) 327-4545
(305) 547-6666
Nathan Slewett, President

Parkinson's Disease Foundation, Inc. (PDF)

650 West 168th Street
New York, New York 10032

(800) 456-6676
(212) 923-4700
Dinah T. Orr, Executive Director
Contact: Sheree Loftus

PEP (Parkinson's Educational Program) USA

1800 Park Newport, #302
Newport Beach, California 92660

(800) 344-7872
(714) 640-0218
Contact: Charlotte Jayne Drake

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)

822 Wayside Lane
Haddonfield, New Jersey 08033

(609) 428-6510
(609) 428-6980
Audrey Thomas, R.N., Francis J. Davis, and Rosalyn M. Davis, Co-chairpersons

RETT SYNDROME

International Rett Syndrome Association, Inc. (IRSA)

8511 Rose Marie Drive
Fort Washington, Maryland 20744

(301) 248-7031
Kathy Hunter, President

SPASMODIC TORTICOLLIS

National Spasmodic Torticollis Association

P.O. Box 873
Royal Oak, Michigan 48068-0873

(313) 775-1367
(313) 547-2189
Contact: Al Shepherd or Harry Sterkel

SPINA BIFIDA

Spina Bifida Association of America (SBAA)

1700 Rockville Pike
Suite 540
Rockville, Maryland 20852

(800) 621-3141
(301) 770-7222
Norman A. Coe, Executive Director

STURGE WEBER SYNDROME

Sturge-Weber Foundation

P.O. Box 460931
Aurora, Colorado 80013

(303) 693-2986
Karen Ball, Executive Director
Contact: Karen or Kirk Ball

TOURETTE SYNDROME

Tourette Syndrome Association, Inc. (TSA)

42-40 Bell Boulevard
Bayside, New York 11361

(718) 224-2999
Dennis Herschfelder, Executive Director
Contact: Jared Bernstein, C.S.W.

TUBEROUS SCLEROSIS

National Tuberous Sclerosis Association (NTSA)

4351 Garden City Drive
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(301) 459-9888
Vicky Whittemore, Ph.D., President

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P.O. Box 1305
Middleboro, Massachusetts 02370

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Neuromuscular Disorders

AMYOTROPHIC LATERAL SCLEROSIS (LOU GEHRIG'S DISEASE)

Amyotrophic Lateral Sclerosis Association (ALSA)

21021 Ventura Boulevard
Suite 321
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CHARCOT-MARIE-TOOTH DISEASE/ PERONEAL MUSCULAR TROPHY

CMT International, Inc.

34-B Bayview Drive
St. Catharines, Ontario L2N 4Y6
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Contact: Karol B. Hitt

DYSTONIA

Benign Essential Blepharospasm Research Foundation, Inc.

P.O. Box 12468
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Sherrie Dominy, Executive Director
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Dystonia Medical Research Foundation (DMRF)

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(213) 852-1630 (California)
Contact: Nancy Harris (California)

777 Hornby Street
Vancouver, British Columbia V6Z 1S4
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Lois Raphael, Executive Director (Canada)

MULTIPLE SCLEROSIS

National Multiple Sclerosis Society

205 East 42nd Street
New York, New York 10017

(212) 986-3240
Thor Hanson, President

MUSCULAR DYSTROPHY

Muscular Dystrophy Association (MDA)

810 Seventh Avenue
New York, New York 10019

(212) 586-0808
Contact: Robert Ross, Vice President

MYASTHENIA GRAVIS

Myasthenia Gravis Foundation

7-11 South Broadway
Suite 304
White Plains, New York 10601

(914) 328-1717
Valerie M. Tennent, Executive Administrator

MYOCLONUS

Myoclonus Families United

1564 East 34th Street
Brooklyn, New York 11234

(718) 252-2133
Sharon Dobkin, President

National Myoclonus Foundation

845 Third Avenue
New York, New York 10022

(212) 758-5656
Burton J. Diamond, President

SPINAL MUSCULAR ATROPHY

Families of S.M.A.

(Adult Progressive Spinal Muscular Atrophy, (Aran-Duchenne Type) Benign Congenital Hypotonia, Kugelberg-Welander Disease, Werdnig-Hoffmann Disease)

P.O. Box 1465
Highland Park, Illinois 60035

(312) 432-5551
Audrey N. Lewis, Executive Director

Respiratory Disorders

GENERAL

American Association for Respiratory Care

1720 Regal Row
Dallas, Texas 75235

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Sam P. Giordano, M.B.A., R.R.T., Executive Director
Contact: Gary L. Peschka, M.Ed., R.R.T., Director of Education

American Lung Association

1740 Broadway
New York, New York 10019-4374

(212) 315-8700
James A. Swomley, Executive Director
Contact: Karen D. Monaco

ALLERGY/ASTHMA

American Academy of Allergy and Immunology (AAAI)

611 East Wells Street
Milwaukee, Wisconsin 53202

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Donald L. McNeil, Executive Director

American Allergy Association (AAA)

P.O. Box 7273
Menlo Park, California 94026

(415) 322-1663
Carol Rudoff, Executive Director

Asthma and Allergy Foundation of America (AAFA)

1717 Massachusetts Avenue
Suite 305
Washington, D.C. 20036

(202) 265-0265
Rebecca Fay, Executive Director

Mothers of Asthmatics, Inc.

5316 Summit Drive
Fairfax, Virginia 22030

(703) 631-0123
Nancy Sander, Executive Director

Short Stature

Human Growth Foundation (HGF)

4720 Montgomery Lane
Bethesda, Maryland 20815

(301) 656-7540
Denise Orenstein, Executive Director

Little People of America, Inc. (LPA)

P.O. Box 633
San Bruno, California 94066

(415) 589-0695
Contact: Harriet or Al Stickney

Skin Disorders

ALOPECIA AREATA

National Alopecia Areata Foundation (NAAF)

714 C Street
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(415) 456-4644
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CONGENITAL PORT WINE STAIN

National Congenital Port Wine Stain Foundation

125 East 63rd Street
New York, New York 10021

(212) 755-3820
Martha Woodhouse, Executive Director

ECTODERMAL DYSPLASIAS

National Foundation for Ectodermal Dysplasias (NFED)

108 North First Street
Suite 311
Mascoutah, Illinois 62558

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Mary Kaye Richter, Executive Director
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EPIDERMOLYSIS BULLOSA

Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.)

c/o Kings County Medical Center
451 Clarkson Avenue
Building E-6-101
Sixth Floor
Brooklyn, New York 11203

(718) 774-8700
Arlene Pessar, R.N., Executive Director

ICHTHYOSIS

Foundation for Ichthyosis and Related Skin Types, Inc. (F.I.R.S.T.)

3640 Grand Avenue
Suite Two
Oakland, California 94610

(415) 763-9839
Charles Eichhorn, Executive Director

SCLERODERMA

United Scleroderma Foundation, Inc. (USF)

P.O. Box 350
Watsonville, California 95077-0350

(800) 722-HOPE
(408) 728-2202
Diane Williams, Executive Director

XERODERMA PIGMENTOSUM

Xeroderma Pigmentosum Registry

UMDNJ - NJ Medical School
Department of Pathology
Medical Science Building
Room C-520
100 Bergen Street
Newark, New Jersey 07103

(201) 456-6255
W. Clark Lambert, M.D., Executive Director

Substance Abuse

American Council for Drug Education (ACDE)

204 Monroe Street
Rockville, Maryland 20852

(301) 294-0600
Lee I. Dogoloff, Executive Director
Contact: Trina Brugger

American Medical Society on Alcoholism and Other Drug Dependencies

12 West 21st Street
Seventh Floor
New York, New York 10010

(212) 206-6770
Contact: Claire Osman

Institute on Black Chemical Abuse (IBCA)

2614 Nicollet Avenue South
Minneapolis, Minnesota 55408

(612) 871-7878
Peter Bell, Executive Director

National Association of State Alcohol and Drug Abuse Directors (NASADAD)

444 North Capitol Street
Suite 530
Washington, D.C. 20001

(202) 783-6868
William Butynski, Executive Director

National Association for Children of Alcoholics (NACOA)

31706 Coast Highway
Suite 201
South Laguna, California 92677-3044

(714) 499-3889
Gerald S. Myers, Executive Director
Contact: Sharon Haight, Information Services Director

National Association for Perinatal Addiction Research and Education (NAPARE)

11 East Hubbard Street
Suite 200
Chicago, Illinois 60611

(312) 329-2512
Ira Chasnoff, M.D., President
Contact: Pat O'Keefe, Communications Director

National Association of Native American Children of Alcoholics (NANACA)

c/o Seattle Indian Health Board
P.O. Box 3364
Seattle, Washington 98104

(202) 324-9360
JoAnn Kauffman, Chairman

National Council on Alcoholism, Inc.

12 West 21st Street
Seventh Floor
New York, New York 10010

(800) NCA-CALL
(212) 206-6770
Thomas V. Seesel, Executive Director

Solvent Abuse Foundation for Education (SAFE)

1500 Rhode Island Avenue, N.W.
Washington, D.C. 20005

(202) 332-7233
Hugh F. Young, President

Stop Teenage Addiction to Tobacco (STAT)

P.O. Box 60658
Long Meadow, Massachusetts 01106

(413) 567-7587
Joe B. Tye, Executive Director

Visual Disorders

BLINDNESS/VISUAL IMPAIRMENT

American Council of the Blind

1010 Vermont Avenue, N.W.
Suite 1100
Washington, DC 20005

(800) 424-8666
(202) 393-3666
Oral O. Miller, National Representative

American Foundation for the Blind, Inc.

15 West 16th Street
New York, New York 10011

(212) 620-2000
William F. Gallagher, Executive Director
Contact: Corinne Kirchner, Director of Social Research

Blind Children's Fund

230 Central Street
Auburndale, Massachusetts 02166-2399

(617) 332-4014
Sherry Raynor, President
Contact: Susan W. Carson, Parent Coordinator

Helen Keller National Center for Deaf-Blind Youths and Adults

111 Middle Neck Road
Sands Point, New York 11050

(516) 944-8900
Steve Barrett, Director

National Association for Parents of the Visually Impaired (NAPVI)

Box 180806
Austin, Texas 78718

(512) 323-5710
Keitha Robinson, Acting Director

National Association for Visually Handicapped

22 West 21st Street
New York, New York 10010

(212) 889-3141
Lorraine H. Marchi, Executive Director

National Society to Prevent Blindness

500 East Remington Road
Schaumburg, IL 60173

(312) 843-2020
Michael Weamer, Executive Director
Contact: Linda Shaub, Director of Marketing and Communications

Vision Foundation, Inc.

818 Mount Auburn Street
Watertown, Massachusetts 02172

(617) 926-4232
Barbara R. Kibler, Executive Director
Contact: Fran Weisse

CATARACTS

Parents and Cataract Kids (PACK)

179 Hunter's Lane
Devon, Pennsylvania 19333

(215) 293-1917
(215) 721-9131
Julie Gerhardt, President
Contact: Elaine Dickenson or Geraldine Miller

RETINAL DEGENERATION

Association for Macular Diseases, Inc.

210 East 64th Street
New York, New York 10021

(212) 605-3719
Nicholai Stevenson, President
Contact: Janet DeRosa

RP Foundation Fighting Blindness

(Retinitis Pigmentosa, Usher Syndrome, Macular Degeneration)

1401 Mount Royal Avenue
Baltimore, Maryland 21217

(800) 638-2300
(301) 225-9400
Robert Gray, Executive Director
Contact: Fran Ludman

Special Health Care Needs

General

National Center for Youth with Disabilities

Adolescent Health Program
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, Minnesota 55455

(800) 333-NCYD
(612) 628-2825
Nancy Okinow, M.S.W., Executive Director

National Resource Institute on Children and Youth with Handicaps (NRICH)

University of Washington
Mailstop WJ-10
Seattle, Washington 98195

(206) 543-2213
Mary Richardson, Ph.D., Executive Director
Barry Mills, Project Manager

National Information Center for Health Related Services

The Center for Developmental Disabilities
University of South Carolina
1244 Blossom Street
Columbia, South Carolina 29208

(800) 922-9234
(803) 777-4435
Girish G. Yajnik, Director

Adoption

AASK America (Aid to Adoption of Special Kids)

1540 Market Street
San Francisco, California 94102

(415) 543-2275
John D. Badger, National Director

Advocacy

Alliance of Genetic Support Groups

38th and R Streets, N.W.
Washington, D.C. 20057

(202) 625-7853
Jayne Mackta, President
Contact: Joan Weiss

National Association of Radiation Survivors (NARS)

78 El Camino Road
Berkeley, California 94705

(415) 654-0010
Dorothy Legarreta, Ph.D., Executive Director

National Organization for Rare Disorders, Inc. (NORD)

P.O. Box 8923
New Fairfield, Connecticut 06812

(203) 746-6518
Abbey S. Meyers, Executive Director

National Organization on Disability (NOD)

910 16th Street, N.W.
Suite 600
Washington, D.C. 20006

(202) 293-5690
(202) 293-5968 (TTD)
Alan A. Reich, President

TASH: The Association for Persons with Severe Handicaps

7010 Roosevelt Way, N.E.
Seattle, Washington 98115

(206) 523-8446
Liz Lindley, Executive Director
Contact: Dian McKernan, Information Specialist

Dental Health for the Disabled

National Foundation of Dentistry for the Handicapped (NFDH)

1259 14th Street
Suite 610
Denver, Colorado 80202

(303) 573-0264
Larry Coffee, D.D.S., Executive Director

Family-Centered Care

Association for the Care of Children's Health (ACCH)

3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016

(202) 244-1801
Beverly H. Johnson, Executive Director

Children In Hospitals, Inc.

31 Wilshire Park
Needham, Massachusetts 02192

(617) 482-2915
Barbara Popper, Executive Director

Children's Hospice International

1101 King Street
Suite 131
Alexandria, Virginia 22314

(800) 242-4453
(703) 684-0330
Ann Armstrong Dailey, Executive Director

Federation for Children with Special Needs

312 Stuart Street
Second Floor
Boston, Massachusetts 02116

(617) 482-2915
Martha H. Ziegler, Executive Director

Make-A-Wish Foundation of America

4601 North 16th Street
Suite 205
Phoenix, Arizona 85016

(602) 234-0960
Jean K. Elder, Ph. D., Executive Director

Make Today Count, Inc.

101 1/2 South Union Street
Alexandria, Virginia 22314-3323

(703) 548-9674
Wanda S. Kelly, Chairman of the Board
Sandra Butler Whyte, Executive Director

National Association for Home Care

519 C Street, N.E., Stanton Park
Washington, D.C. 20002

(202) 547-7424
Val J. Halamandaris, President

National Association of Children's Hospitals and Related Institutions (NACHRI)

401 Wythe Street
Alexandria, Virginia 22314

(703) 684-1355
Robert H. Sweeney, President
Contact: Patricia Sealing, Director of Child Health Analysis

National Hospice Organization (NHO)

1901 North Fort Myer Drive
Suite 307
Arlington, Virginia 22209

(703) 243-5900
John J. Mahoney, Executive Director

National Maternal and Child Health Resource Center

College of Law Building
The University of Iowa
Iowa City, Iowa 52242

(319) 355-9067
John C. MacQueen, M.D., Director
Josephine Gittler, J.D., Co-Director

National Parent Chain (Coalition for Handicapped Americans Information Network)

90 East Wilson Bridge Road
Suite 297
Worthington, Ohio 43085

(614) 431-1911
Margaret Burley, Executive Director
Contact: Donna Owens

Parentele

5538 North Pennsylvania Street
Indianapolis, Indiana 46220

(317) 259-1654
Pat Koerber, Acting Director

Sibling Information Network

Connecticut's University Affiliated Program
on Developmental Disabilities
University of Connecticut
249 Glenbrook Road
Storrs, Connecticut 06268

(203) 486-3783
Kathleen Bradley, Coordinator

SKIP (Sick Kids need Involved People), Inc.

216 Newport Drive
Severna Park, Maryland 21146

(301) 261-2602
Karen A. Shannon, Executive Director

Recreation

National Recreation and Park Association
National Therapeutic Recreation Society

3101 Park Center Drive
12th Floor
Alexandria, Virginia 22302

(703) 820-4940
Dean Tice, Executive Director

Special Olympics International

1350 New York Avenue, N.W.
Suite 500
Washington, D.C. 20005

(202) 393-1250
Sargent Shriver, President

Very Special Arts

Education Office
John F. Kennedy Center for the Performing Arts
Washington, D.C. 20566

(202) 662-8899 (Voice)
(202) 662-8898 (TTD)
Eugene C. Maillard, Chief Executive Officer
Contact: Kathy Winslow, Public Information Coordinator

Rehabilitation

American Occupational Therapy Association, Inc. (AOTA)

1383 Piccard Drive
Suite 301
Rockville, Maryland 20850

(301) 948-9626
Jeanette Bair, Executive Director
Contact: Barbara Hanft

American Physical Therapy Association (APTA)

1111 North Fairfax Street
Alexandria, Virginia 22314

(703) 684-2782
Eugene Michaels, Interim Executive Director

Council of State Administrators of Vocational Rehabilitation

P.O. Box 3776
Washington, D.C. 20007

(202) 638-4634
Joseph H. Owens, Jr., Executive Director

National Easter Seal Society

2023 West Ogden Avenue
Chicago, Illinois 60612

(312) 243-8400 (Voice)
(312) 243-8880 (TDD)
John R. Garrison, Executive Director
Contact: Jan Bakker

National Rehabilitation Association

633 South Washington Street
Alexandria, Virginia 22313

(703) 836-0850
David L. Mills, Executive Director

National Rehabilitation Information Center (NARIC)

8455 Colesville Road
Suite 935
Silver Spring, Maryland 20910-3319

(301) 588-9284
Dr. Richard Diener, Director

Rehabilitation International

25 East 21st Street
New York, New York 10010

(212) 420-1500
Susan R. Hammerman, Secretary General

Sexuality

Coalition on Sexuality and Disability

853 Broadway
Suite 611
New York, New York 10003

(212) 242-3900
Thomas-Robert H. Ames, President

Special Education

American Council on Rural Special Education (ACRES)

Miller Hall 359
Western Washington University
Bellingham, Washington 98225

(206) 676-3576
Doris Helge, Ph.D., Executive Director

Council for Exceptional Children (CEC)

1920 Association Drive
Reston, Virginia 22091

(703) 620-3660
Jeptha Greer, Executive Director

National Association of State Directors of Special Education (NASDSE)

2021 K Street, N.W.
Suite 315
Washington, D.C. 20006

(202) 296-1800
William V. Schipper, Executive Director

National Information Center for Children and Youth with Handicaps (NICHCY)

P.O. Box 1492
Washington, D.C. 20013

(703) 893-6061
Carol Valdivieso, Project Director

Public Health Programs and Services

General

American Public Health Association (APHA)

1015 15th Street, N.W.
Washington, D.C. 20005

(202) 789-5600
William H. McBeath, M.D., M.P.H. Executive Director
Contact: Julie Gazmararian, M.P.H.

Association of State and Territorial Health Officials (ASTHO)

6728 Old McLean Village Drive
Washington, D.C. 22101

(202) 556-9222
George K. Degnon, Executive Director

Association of Teachers of Maternal and Child Health (ATMCH)

Division of Maternal and Child Health
San Diego State University
San Diego, California 92182

(619) 594-4493
Allan C. Oglesby, M.D., M.P.H., President

Public Health Foundation

1220 L Street, N.W.
Suite 350
Washington, D.C. 20005

(202) 898-5600
Gary J. Clarke, Executive Director

Community Health

Association of Asian/Pacific Community Health Organizations (AAPCHO)

310 Eighth Street
Suite 200
Oakland, CA 94607

(415) 272-9536
Laurin Mayeno, Executive Director

National Association of Community Health Centers (NACHC)

1625 I Street, N.W.
Suite 420
Washington, D.C. 20006

(202) 883-9280
Thomas Van Coverden, Executive Director

National Association of Counties

440 First Street, N.W.
Eighth Floor
Washington, D.C. 20001

(202) 893-6226
John P. Thomas, Executive Director

National Association of County Health Officials

440 First Street, N.W.
Washington, D.C. 20001

(202) 783-5550
Nancy Rawding, Executive Director

National League of Cities

1301 Pennsylvania Avenue, N.W.
Washington, D.C. 20004

(202) 626-3000
Alan Beals, Executive Director

National Migrant Referral Project, Inc.

2512 South IH-35
Suite 220
Austin, Texas 78704

(512) 447-0770
E. Roberta Ryder, Executive Director

National Rural Health Care Association (NRHA)

301 East Armour Boulevard
Suite 420
Kansas City, Missouri 64111

(816) 756-3140
Robert T. Van Hook, Executive Director
Contact: Barbara A. Schaaf, Publications Coordinator

Refugee Health Issues Center

c/o American Refugee Committee
2344 Nicollet Avenue
Suite 350
Minneapolis, Minnesota 55404

(612) 872-7060
Garth Osborn, Manager

Health Care Financing

American Public Welfare Association State Medicaid Directors' Association

1810 First Street, N.E.
Suite 500
Washington, D.C. 20002-4205

(202) 682-0100
A. Sidney Johnson, III, Executive Director

National Conference of State Legislatures

1050 17th Street
Suite 2100
Denver, Colorado 80265

(303) 623-7800
William Pound, Executive Director

National Governors' Association

444 North Capitol Street
Suite 250
Washington, D.C. 20001

(202) 624-5300
Raymond C. Scheppach, Executive Director

Health Policy

Intergovernmental Health Policy Project

2011 I Street
Suite 200
Washington, D.C. 20006

(202) 872-1445
Richard E. Merritt, Executive Director

McManus Health Policy, Inc.

4801 Massachusetts Avenue, N.W.
Suite 400
Washington, D.C. 20016

(202) 895-1580
Peggy McManus, Executive Director

National Association for Public Health Policy (NAPHP)

208 Meadowood Drive
South Burlington, Vermont 05403

(802) 658-0136
Milton Terris, M.D., President

National Center for Social Policy and Practice

7981 Eastern Avenue
Silver Spring, Maryland 20910

(301) 565-0333
Contact: Jim McTique, Ph.D.

Office of Family Policy and Support
Assistant Secretary of Defense
Force Management and Personnel

4015 Wilson Boulevard
Suite 903
Arlington, Virginia 22203

(202) 696-4555
Contact: Kathleen Furukawa

Health Promotion

American College of Preventive Medicine

1015 15th Street, N.W.
Suite 403
Washington, D.C. 20005

(202) 789-0003
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American Occupational Medical Association (AOMA)

2340 South Arlington Heights Road
Arlington Heights, Illinois 60005

(312) 228-6850
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Association for the Advancement of Heath Education

1900 Association Drive
Reston, Virginia 22304

(703) 476-3437
Becky J. Smith, Executive Director

National Center for Health Education (NCHE)

30 East 29 Street
New York, New York 10016

(212) 689-1886
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Contact: William Gross, Director of Communications

National Council on Patient Information and Education (NCPIE)

1625 I Street, N.W.
Suite 1010
Washington, D.C. 20006

(202) 466-6711
Robert M. Bachman, Executive Director

National Wellness Association

University of Wisconsin—Stevens Point
South Hall
Point, Wisconsin 54481

(715) 346-2172
David A. Emmerling, Ed. D., Executive Stevens Director
Contact: Patrick Salaski, Assistant Director

Native Americans

American Indian Health Care Association (AIHCA)

245 East Sixth Street
Suite 815
St. Paul, Minnesota 55101

(612) 293-0233
William LaRoque, Executive Director

National Indian Health Board

50 South Steele
Suite 500
Denver, Colorado 80209

(303) 394-3500
Jake Whitecrow, Executive Director

State Maternal and Child Health Programs

Association of Maternal and Child Health Programs (AMCHP)

2001 L Street, N.W.
Suite 308
Washington, D.C. 20036

(202) 775-0436
Catherine Hess, Director

National Center for Education in Maternal and Child Health (NCEMCH)

38th and R Streets, N.W.
Washington, D.C. 20057

(202) 625-8400
Robert C. Baumiller, S.J., Ph.D., Director
Rochelle Mayer, Ed.D., Program Director

National Maternal and Child Health Resource Center

College of Law Building
The University of Iowa
Iowa City, Iowa 52242

(319) 355-9067
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Josephine Gitler, J.D., Co-Director

Health Care Providers

American Academy of Family Physicians (AAFP)

1740 West 92nd Street
Kansas City, Missouri 64114

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American Academy of Pediatric Dentistry (AAPD)

211 East Chicago Avenue
Suite 1036
Chicago, Illinois 60611

(312) 337-2169
Dr. John A. Bogert, Executive Director

American Academy of Pediatrics (AAP)

141 Northwest Point Boulevard
P.O. Box 927
Elk Grove Village, Illinois 60007

(312) 228-5005
James Strain, M.D., Executive Director
Contact: Candance Croft, Ph.D.

American College of Nurse-Midwives

1522 K Street, N.W.
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Mary Rita Prah, Executive Director

American College of Obstetricians and Gynecologists (ACOG)

409 12th Street, S.W.
Washington, D.C. 20024-2188

(202) 638-5577
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Contact: Marvin J. Bennof

American Dental Association (ADA)

211 East Chicago Avenue
Chicago, Illinois 60611

(312) 440-2500
Thomas J. Ginley, Ph.D., Executive Director

American Dental Hygienists Association (ADHA)

444 North Michigan Avenue
Suite 3400
Chicago, Illinois 60611

(312) 440-8900
Dr. Albert J. Sunseri, Executive Director

American Dietetic Association (ADA)

208 South LaSalle Street
Suite 1100
Chicago, Illinois 60604-1003

(312) 899-0040
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Contact: Karen A. Lechowich, R.D.

American Hospital Association (AHA)

840 North Lake Shore Drive
Chicago, Illinois 60611

(312) 280-6000
Carol M. McCarthy, Ph.D., J.D., President

American Medical Association (AMA)

535 North Dearborn Street
Chicago, Illinois 60610

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(312) 645-4663
Donald R. Bennett, M.D., Ph.D., Executive Director
Contact: Charles Macenski

American Nurses' Association (ANA)

2420 Pershing Road
Kansas City, Missouri 64108

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American Occupational Therapy Association, Inc. (AOTA)

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Contact: Barbara Hanft

American Physical Therapy Association (APTA)

1111 North Fairfax Street
Alexandria, Virginia 22314

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American Psychological Association (APA)

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Contact: Julie Gazmararian, M.P.H.

American Society of Human Genetics (ASHG)

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Bethesda, Maryland 20814

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Gerry Gurvitch, Executive Director

Council of Social Work Education (CSWE)

1744 R Street, N.W.
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(202) 667-2300
Donald Beless, Ph.D., Executive Director

Emergency Nurses Association (ENA)

230 East Ohio, #600
Chicago, Illinois 60611

(312) 649-0297
Torry Mark Sansone, Executive Director

International Society of Nurses in Genetics (ISNG)

Division of Medical Genetics
University of Iowa Hospitals and Clinics
Iowa City, Iowa 52242

(319) 356-2674
Elizabeth Thomson, R.N., M.S., President

Midwives Alliance of North America (MANA)

30 South Main Street
Concord, New Hampshire 03301

(603) 225-9586
Carol Leonard, Executive Officer

National Association of EMS (Emergency Medical Services) Physicians

Center for Emergency Medicine
190 Lothrop Street, Room 113
Pittsburgh, Pennsylvania 15213

(800) 228-3677
Paul M. Paris, M.D., F.A.C.E.P., President

National Association of Pediatric Nurse Associates and Practitioners (NAPNAP)

1000 Maplewood Drive
Suite 104
Shade, New Jersey 08052-1931

(609) 667-1773
Mavis L. McGuire, R.N., M.A., C.P.N.P., Maple
Executive Director
Contact: Joan Rukavina, National Office
Manager

National Association of Social Workers, Inc. (NASW)

7981 Eastern Avenue
Silver Spring, Maryland 20910

(301) 565-0333
Mark Battle, Executive Officer

National Black Nurses' Association

1011 North Capitol Street, N.E.
Washington, D.C. 20002

(202) 898-5232
Sadako S. Holmes, Executive Director

National Coalition of Hispanic Mental Health and Human Services Organizations (COSSHMO)

1030 15th Street, N.W.
Suite 1053
Washington, D.C. 20005

(202) 371-2100
Contact: Helen Munoz

National League for Nursing (NLN)

Ten Columbus Circle
New York, New York 10019

(212) 582-1022
Pamela Maraldo, R.N., Executive Director

National Medical Association (NMA)

1012 Tenth Street, N.W.
Washington, D.C. 20001

(202) 347-1895
William C. Garrett, Executive Vice-President

National Society of Genetic Counselors (NSGC)

233 Canterbury Drive
Wallingford, Pennsylvania 19086

(215) 872-7608
Bea Leopold, Executive Director

NAACOG: The Organization for Obstetric, Gynecologic, and Neonatal Nurses

409 12th Street, S.W.
Washington, D.C. 20024-2191

(800) 533-8822
(202) 638-0026
Sallye B. Shaw, R.N., M.N., Executive Director
Contact: Kay Hartman Tucker

Society for Adolescent Medicine (SAM)

P.O. Box 3462
Granada Hills, California 91344

(818) 368-5996
Richard C. Brown, M.D., Executive Director

Part II

Self-Help Clearinghouses

96

Self-help groups offer people who face a common problem the opportunity to meet with others and share experiences, knowledge, strengths, and hopes. Self-help clearinghouses collect and disseminate information about local self-help groups and assist people in forming new groups. Self-help clearinghouses differ in their ability to provide information and referrals. This list of self-help clearinghouses is organized by state. If you are unable to locate a service to meet your needs, we suggest you contact your state mental health association. In addition, the National Self-Help Clearinghouse, the New Jersey Self-Help Clearinghouse, or the National Center for Education in Maternal and Child Health may be able to provide a referral.

UNITED STATES

National

National Self-Help Clearinghouse

Graduate School and University Center
of the City University of New York
33 West 42nd Street
Room 1227
New York, New York 10036

(212) 840-1258/9
Frank Riessman, Director

California

Bay Area Self-Help Clearinghouse

Mental Health Association
2398 Pine Street
San Francisco, California 94115

(415) 921-4401
Mara Weiss, Coordinator

California Self-Help Center

University of California - Los Angeles
2349 Franz Hall
405 Hilgard Avenue
Los Angeles, California 90024

(800) 222-LINK
(213) 825-1799
Mark Mayeda, Bonnie Burstein,
Co-Directors

Merced County Self-Help Clearinghouse

Mental Health Association
P.O. Box 343
Merced, California 95341

(209) 723-8861
Geri Steward, Coordinator

Mental Health Association of Contra Costa

604 Ferry Street
Martinez, California 94553

(415) 229-0444

Sacramento Self-Help Clearinghouse

Mental Health Association
5370 Elvas Avenue
Suite B
Sacramento, California 95819

(916) 456-2070
Pat Camper, Coordinator

Tri-County Clearinghouse (Placer, Yolo, Sacramento)

Mental Health Association
P.O. Box 447
Davis, California 95617

(916) 756-8181
Elaine Talley, Coordinator

Connecticut

Connecticut Self-Help/Mutual Support Network

Consultation Center
19 Howe Street
Haven, Connecticut 06511

(203) 789-7645
Marvin Steinberg, Sophie Tworkowski,
Co-Directors
Contact: Vicki Spiro Smith, Coordinator

Illinois

Self-Help Center

1600 Dodge Avenue, Suite S-122
Evanston, Illinois 60201

(312) 328-0470
Daryl Isenberg, Ph.D. Director

Kansas

Self-Help Network

Campus Box 34
Wichita State University
Wichita, Kansas 67208-1595

(316) 686-1205
Evelyn Middelstadt, Executive Director
David F. Gleason, Director

Massachusetts

Boston Self Help Center

18 Williston Road
Brookline, Massachusetts 02146

(617) 277-0080
Concetta Panzarino, Executive Director

Massachusetts Clearinghouse of Mutual Support Groups

Massachusetts Cooperative Extension
113 Skinner Hall
University of Massachusetts
Amherst, Massachusetts 01003

(413) 545-2313
Warren Schumacher, Director
Thomas Zink, Coordinator

Michigan

Michigan Self-Help Clearinghouse

Michigan Protection and Advocacy Service
109 West Michigan Avenue
Suite 900
Lansing, Michigan 48933

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Subject Index

Accident/Injury Prevention, 11
Achondroplasia, see Short Stature
Acoustic Neuroma, 55
Acquired Immune Deficiency Syndrome, 47
Adolescent Medicine, 18, 85
Adolescent Pregnancy, 19
Adoption, 11, 70
Adrenoleukodystrophy, see Leukodystrophy
Adult Progressive Spinal Muscular Atrophy (Aran Ducenne Type),
Affective Disorders, see Depression
AIDS, see Acquired Immune Deficiency Syndrome
Alagille Syndrome, see Liver Disorders
Albinism, 48
Alcoholism, 66
Alexander Disease, see Leukodystrophy
Allergy, 63
Alopecia Areata, 64
Alpha-1-Antitrypsin Deficiency, see Liver Diseases
Alzheimer Disease, 55
American Indians, see Native Americans
Amyotrophic Lateral Sclerosis, 61
Angleman Syndrome, 55
Anorexia Nervosa, 42
Argininosuccinic Acidemia, see Organic Acidemia
Arthritis, 53
Arthrogryposis, 53
Artificial Insemination, 6
Asian Americans, 76
Asthma, 63
Ataxia, 55
Ataxia Telangiectasia, see Ataxia
Auditory Disorders, 29
Autism, 38

Bardet-Biedl Syndrome, see Laurence-Moon-Biedl Syndrome
Bassen-Kornzweig Syndrome, see Retinal Degeneration
Batten Disease, 56
Behavioral Problems, 20
Benign Congenital Hypotonia, 62
Bereavement, 4
Best Disease, see Retinal Degeneration
Biliary Atresia, see Liver Disorders
Birth Defects, 6, 29
Birth Settings, 1
Birth Parents, 11
Blacks, 24, 66, 84
Blepharospasm, 61
Blindness, see Visual Disorders
Blood Banks, 33
Bradley Method, 2
Brain Tumor, 32
Breast Cancer, 32
Breastfeeding, 7

Bulimia, 42

Canavan Disease, see Leukodystrophy, Tay Sachs and Allied Diseases
Cancer, 31
Cardiology, 33
Cardiovascular Disorders, 33
Cataracts, 68
Cat Cry Syndrome, see Cri-du-Chat Syndrome
Celiac Disease, 42
Celiac Sprue, 42
Cerebral Palsy, 38
Cesarean Birth, 2
Cerebrotendinous Xanthomatosis, see Leukodystrophy
Chanarin-Dorfman Syndrome, see Ichthyosis and Related Skin Types
Charcot-Marie-Tooth Disease, 61
Chediak-Higashi Syndrome, see Albinism
Child Abuse/Neglect, 12
Child Care, 13
Child Development, 14
Child Syndrome , see Ichthyosis and Related Skin Types
Childbearing Centers, 2
Childbirth Assistants, 5
Childbirth Preparation, 2
Childhood Cancer, 32
Child Health, 10
Children of Alcoholics, 66
Children's Hospitals, 16, 71
Chondrodysplasia Punctata Syndromes, see Ichthyosis and Related Skin Types
Choroidermia, see Retinal Degeneration
Chromosomal Abnormalities, 33
Chronic Fatigue Immune Dysfunction, 46
Circumcision, 4
Clearinghouses, 87
Cleft Lip/Palate,
Cockayne Syndrome, 39
Colitis, 43
College Health, 21
Collodian Fetus, see Ichthyosis and Related Skin Types
Colon Cancer, see Gastrointestinal Polyposis
Colorectal Cancer, see Gastrointestinal Polyposis
Community Health, 76
Community Health Centers, 76
Contraception, 24
Congenital Heart Defects, see Cardiovascular Disorders
Congenital Ichthyosiform Erythroderma (CIE), see Ichthyosis and Related SkinTypes
Congenital Port Wine Stain, 64
Connective Tissue Disorders, 35
Cooley's Anemia, see Thalassemia
Cornelia de Lange Syndrome, 39
County Health Officials, 77
Craniofacial Disorders, 36
Crest Syndrome, see Scleroderma
Cri-du-Chat Syndrome, 33

Crouzon Syndrome, see Craniofacial Anomalies
Crohn Disease, see Ileitis
Custody, 15
Cystic Fibrosis, 49
Cystinosis, 49
Cystitis, 43
Cytogenetic Technologists, 28

Darier Disease, see Ichthyosis and Related Skin Types
Day Care, 13
Deafness, see Auditory Disorders
Dementia, see Alzheimer Disease
Dental Health, 13, 71, 81
Dental Hygienists, 14, 81
Dentistry, 13
Depression, 48
Dermatitis Herpetiformis, see Celiac Disease
Dermatomyositis, see Muscular Dystrophy
DES, 25
Development, 14
Developmental Disabilities, 38, 70
Diabetes, 49
Diethylstilbestrol, see DES
DiGeorge Syndrome, see Immune Deficiency
Digestive Diseases, see Gastrointestinal Disorders
Domestic Violence, 24
Down Syndrome, 34
Drug Dependencies, 66
Drug Education, 66
Dwarfing Syndromes, see Short Stature
Dysautonomia, 49
Dyslexia, 40
Dystonia, 61

Eating Disorders, 42
Ectodermal Dysplasias, 64
Education, 14, 21
Edwards Syndrome, see Trisomy 18/13
Ehlers-Danlos Syndrome, 35
Emergency Medical Services, 10, 83
Endometriosis, 26
Epidermal Nevus Syndrome, see Ichthyosis and Related Skin Types
Epidermolysis Bullosa, 65
Epidermolytic Hyperkeratosis, see Ichthyosis and Related Skin Types
Epilepsy, 56
Epstein-Barr Virus, see Chronic Fatigue Immune Dysfunction
Erythrokeratodermia Progressiva Symmetrica, see Ichthyosis and Related Skin Types
Ethylmalonic Adipic Acidemia, see Organic Acidemia

Facial Dystonia, see Blepharospasm
Facial Reconstruction, 36
Familial Adenomatous Polyposis, see Gastrointestinal Polyposis

Familial Dysautonomia, see Dysautonomia
Familial Polyposis, see Gastrointestinal Polyposis
Family-Centered Care, 13
Family Conflict, 12, 24
Family Physicians, 81
Family Planning, 24
Family Relations, 16
Family Support, 18
Fanconi Anemia, 43
Fertility, 24
Fibrodysplasia Ossificans Progressiva, 36
5p-, see Cri-du-Chat Syndrome
Fragile X Syndrome, 34
Freeman-Sheldon Syndrome, 54
Friedrich Ataxia, 55

Galactosemia, 50
Gangliosidosis, see Tay-Sachs and Allied Dieseases
Gardner Syndrome, see Gastrointestinal Polyposis
Gastrointestinal Disorders, 42
Gastrointestinal Polyposis, 32
Gaucher Disease, 50
Genetic Counselors, 28
Genetic Disorders, 29
Genetic Services, 28
Gilbert Syndrome, see Liver Disorders
Genitourinary Disorders, 43
Gluten Intolerance, 42
Glycogen Storage Disease, 50
Growth, see Short Stature
Guillain-Barré Syndrome, 56
Gynecologists, 1, 25, 81

Haitians, 92
Harlequin Fetus, see Ichthyosis
Head Injury, 10, 57
Health Education, 79
Health Policy, 78
Health Promotion, 79
Hearing Impairments, see Auditory Disorders
Heart Murmur, see Cardiovascular Disorders
Hematologic Disorders, 43
Hemochromatosis, 44
Hemodialysis, 47
Hemophilia, 44
Hereditary Colon Cancer, see Gastrointestinal Polyposis
Hereditary Hemorrhagic Telangiectasia, 44
Hereditary Motor and Sensory Neuropathy, see Charcot-Marie-Tooth Disease
Hereditary Spastic Paraplegia, see Ataxia
Hermansky-Pudlak Syndrome, see Albinsm
Hispanics, 84
Histiocytosis-X, 45

Homebirth, 1
Home Care, 72
Home Economics, 27
Homocystinuria, see Organic Acidemia
Hospitals, 16, 71, 82
Hospice, 72
Human Genetics, 28
Human Growth, 64
Hunter Syndrome, see Mucopolysaccharidoses
Huntington Disease, 57
Hurler Syndrome, see Mucopolysaccharidoses
Hydrocephalus, 57
Hyperactivity, 39
Hypopigmentation, see Albinism

I-Cell Syndrome, see Mucopolysaccharidoses
Ichthyosis and Related Skin Types, 65
Ileitis, 43
Immune Deficiency, 46
Immunologic Disorders, 46
Immunology, 46
Indian Health Care, 66, 80
Infant Loss, 4
Infant Mortality, 7
Infectious Diseases, 47
Infertility, 26
Inflammatory Bowel Disease (IBD), see Ileitis
Inflammatory Myopathies, see Muscular Dystrophy
Interstitial Cystitis, 43
Intestinal Multiple Polyposis, see Gastrointestinal Polyposis
Intrauterine Growth Retardation, see Human Growth
Intraventricular Hemorrhage, 8
Iron Overload Disorders, 44
Isovaleric Acidemia, see Organic Acidemia

Jewish Genetic Diseases, 29
Joseph Diseases, 58
Juvenile Arthritis, 53
Juvenile Diabetes, 49
Juvenile Polyposis, see Gastrointestinal Polyposis

Keratitis-Ichthyosis-Deafness (KID) Syndrome, see Ichthyosis and Related Skin Types
Kidney Diseases, 47
Klippel-Trenaunay-Weber (K-T) Syndrome, 39
Krabbe Disease, see Leukodystrophy, Tay-Sachs and Allied Diseases
Kugelberg-Welander Disease, 62
Kyphosis, see Scoliosis

Lactation, 7
Lamaze, 2
Lamellar Ichthyosis, see Ichthyosis and Related Skin Types
Laurence-Moon-Biedl Syndrome, 39

Learning Disabilities, 40
Leber Amaurosis, see Retinal Degeneration
Leukemia, 33
Leukodystrophy, 50
Liver Disorders, 43
Lordosis, see Scoliosis
Lou Gehrig's Disease, see Amyotrophic Lateral Sclerosis
Lowe Syndrome, 50
Lupus, 46
Lysosomal Storage Diseases, see Tay-Sachs and Allied Diseases

Macular Degeneation, 69
Macular Diseases, 69
Mallignant Hyperthermia, 51
Manic Depression, see Depression
Maple Syrup Urine Disease, 51
Marfan Syndrome, 36
Maroteaux-Lamy Syndrome, see Mucopolysaccharidoses
Maternal and Child Health Programs, 76, 80
Maternity Centers, 1
Meige Lymphedema, see Blepharospasm
Menkes Disease, 53
Mental Health, 47
Mental Illness, 41, 48
Mental Retardation, 40
Metabolic Disorders, 48
Metachromatic Leukodystrophy, see Leukodystrophy, Tay-Sachs and Allied Diseases
Methylmalonic Acidemia, see Organic Acidemia
Midwifery, 1, 6, 83
Migrant, 77
Military Families, 78
Minorities, see Asian Americans, Native Americans, Blacks, Haitians
Monosomy 9p, 35
Montessori, 14
Morquio Syndrome, see Mucopolysaccharidoses
Motor Neuron Diseases, see Muscular Dystrophy
Mucolipidoses, 51
Mucolipidosis IV, 51
Mucopolysaccharidoses, 51
Multiple Birth, 3
Multiple Personalities, 48
Multiple Sclerosis, 62
Multiple Sulfatase Deficiency, see Ichthyosis and Related Skin Types
Muscular Dystrophy, 62
Musculoskeletal Disorders, 53
Myasthenia Gravis, 62
Myelomeningocele, see Spina Bifida
Myoclonus, 62
Myotonia Congenita, see Muscular Dystrophy
Myotonic Dystrophy, see Muscular Dystrophy
Myotubular Myopathy, see Muscular Dystrophy

Nannies, 13

Narcolepsy, 58
Native Americans, 66, 80
Neonatal Addiction, see Perinatal Addiction
Neonatal Adrenoleukodystrophy, see Leukodystrophy
Neural Tube Defects, see Spina Bifida
Neurofibromatosis, 58
Neurologic Disorders, 55
Neurology, 55
Neuro-metabolic Disorders, 51
Neuromuscular Disorders, 61
Neuronal Ceroid Lipofuscinoses, see Batten Disease
Niemann-Pick Disease, see Tay-Sachs and Allied Diseases
Nurses, 1, 10, 16, 22, 26
Nutrition, 27
Nutrition Education, 27

Obstetrics, 1, 25, 81
Occupational Health, 24, 79
Occupational Therapy, 74
Organic Acidemia, 52
Orthopedics, 53
Orthopsychiatry, 48
Osler-Weber-Rendu Syndrome, see Hereditary Hemorrhagic Telangiectasia
Osteogenesis Imperfecta, 54

Paget Disease, 54
Parenting, 1, 8, 15
Parkinson Disease, 58
Patau Syndrome, see Trisomy 13
Patient Education, 79
Pediatric Dentistry, 13, 81
Pediatric Nurses, 16, 22
Pediatrics, 16
Peeling Skin Syndrome, see Ichthyosis and Related Skin Types
Pelizaeus-Merzbacher Disease, see Leukodystrophy
Perinatal Addiction, 66
Perinatal Bereavement, 4
Perinatal Care, 4
Peroneal Muscular Atrophy, see Charcot-Marie-Tooth Disease
Peutz-Jeghers Syndrome, see Gastrointestinal Polyposis
Pierre Robin Sequence, see Cleft Lip/Palate
Pityriasis Rubra Pilaris, see Ichthyosis and Related Skin Types
Polycystic Kidney Disease, 47
Pompe Disease, see Glycogen Storage Disease
Porphyria, 52
Port Wine Stain, see Congenital Port Wine Stain
Poverty, 12
Prader-Willi Syndrome, 35
Pregnancy, 1, 19
Pregnancy Loss, 4
Prematurity, 8
Prenatal Care, 5
Preventive Medicine, 79

Progeria, 41
Propionic Acidemia, see Organic Acidemia
Pseudoxanthoma Elasticum, 36
Public Health, 76

Radiation, 70
Raynaud Phenomenon, see Scleroderma
Recreation, 73
Reflex Sympathetic Dystrophy Syndrome, 59
Refsum Disease, see Ichthyosis and Related Skin Types, Leukodystrophy, Retinal Degeneration
Refugee Health, 77
Rehabilitation, 74
Reproductive Hazards, 6
Reproductive Health, 25
Reproductive Technologies, 6
Respiratory Care, 63
Respiratory Disorders, 63
Retinal Degeneration, 69
Retinitis Pigmentosa, 69
Rett Syndrome, 59
Reye Syndrome, 17
Rheumatic Diseases, see Arthritis
Rheumatic Fever, see Cardiovascular Disorders
Riley-Day Syndrome, see Dysautonomia
Rubinstein-Taybi Syndrome, 41
Rural Health, 77

Sandhoff Disease, see Tay-Sachs and Allied Diseases
Sanfilippo Syndrome, see Mucopolysaccharidoses
Sarcoidosis, see Liver Disorders
Schele Syndrome, see Mucopolysaccharidoses
School-Based Clinics, 18, 21
School Health, 21
Scleroderma, 65
Scoliosis, 54
Self-Help, 87
Sex Education, 26
Sexuality, 75
Short Stature, 64
Sialicosis, see Mucolipidoses
Siblings, 73
Sickle Cell Disease, 45
SIDS, 8
Sjogren Syndrome, 46
Sjogren-Larsson Syndrome, see Ichthyosis and Related Skin Types
Skin Disorders, 64
Sleep Apnea, see Narcolepsy
Sly Syndrome, see Mucopolysaccharidoses
Social Work, 83, 84
Solvent Abuse, 67
Spasmodic Torticollis, 59
Special Education, 75
Special Health Care Needs, 70

Speech, 30
Spina Bifida, 60
Spinal Muscular Atrophy, 62
Stargardt Disease, see Retinal Degeneration
Stepfamilies, 16
Stillborns, 4
Sturge Weber Syndrome, 60
Substance Abuse, 66
Sudden Infant Death Syndrome, 8
Suicide Prevention, 20
Systemic Lupus Erythematosus, see Lupus

Tay-Sachs and Allied Diseases, 52
Television, 14
Teratology, 6
Thalassemia, 45
Thrombocytopenia Absent Radius Syndrome, 45
Thomsen Disease, see Muscular Dystrophy
Tinnitus, 31
Tobacco, 67
Tourette Syndrome, 60
Transplantation, 47
Trauma, 10
Treacher Collins Syndrome, see Craniofacial Disorders
Triplets, 3
Trisomy 18, 35
Trisomy 13, 35
Trisomy 21, see Down Syndrome
Tuberous Sclerosis, 60
Turner Syndrome, 35
Twins, 3

Ulcerative Colitis, see Ileitis
Unilateral Congenital Ichthyosiform Erythroderma, see Ichthysosis and Related Skin Types
Usher Syndrome, 69

Visual Disorders, 67
Visual Impairment, 67
Vitiligo, see Albinism,
von Willebrand Disease, see Hemophilia

Waardenbrug Syndrome, see Albinism
Wellness, 79
Werdnig-Hoffman Disease, 62
Williams Syndrome, 52
Wilson Disease, 53
Women's Health, 24

Xeroderma Pigmentosum, 65

Zellweger Syndrome, see Leukodystrophy

Organization Index

A.M.E.N.D. (Aiding a Mother and Father Experiencing Neonatal Death), 4
AASK America (Aid to Adoption of Special Kids), 11, 70
Aboutface, 37
Acoustic Neuroma Association (ANA), 55
Action Alliance for Children, 13
Action for Children's Television, 14
Alan Guttmacher Institute, 24
Alexander Graham Bell Association for the Deaf (AGBAD), 29
Alliance of Genetic Support Groups, 70
Alzheimer's Disease and Related Disorders Association (ADRDA), 55
Ambulatory Pediatrics Association, 10
American Academy of Allergy and Immunology (AAAI), 63
American Academy of Family Physicians (AAFP), 81
American Academy of Husband Coached Childbirth (Bradley Method), 2
American Academy of Neurology, 55
American Academy of Orthopaedic Surgeons, 53
American Academy of Pediatric Dentistry (AAPD), 13, 81
American Academy of Pediatrics (AAP), 7, 10, 16, 27, 80
American Allergy Association (AAA), 63
American Anorexia/Bulimia Association, Inc. (AABA), 42
American Association for Protecting Children (AAPC), 12
American Association for Respiratory Care, 63
American Association of Blood Banks (AABB), 33
American Association of School Administrators, 21
American Association of University Affiliated Programs for Persons with Development Disabilities (AAUAP), 38
American Association on Mental Retardation (AAMR), 40
American Cancer Society, 31
American Celiac Society, 42
American Cleft Palate Association (ACPA)/The Cleft Palate Foundation, 37
American College Health Association, 21
American College of Cardiology, 33
American College of Nurse Midwives, 1, 81
American College of Obstetricians and Gynecologists (ACOG), 1, 25, 81
American College of Preventive Medicine, 79
American Council for Drug Education (ACDE), 66
American Council of Nanny Schools, 13
American Council of the Blind, 67
American Council on Rural Special Education (ACRES), 75
American Dental Association (ADA), 14, 81
American Dental Hygenists Association (ADHA), 14, 81
American Diabetes Association, Inc., 49
American Dietetic Association (ADA), 27, 82
American Digestive Disease Society (ADDS), 42
American Fertility Society (AFS), 25
American Foundation for the Blind, Inc., 67
American Home Economics Association (AHEA), 27
American Hospital Association, 82
American Indian Health/Care Association (AIHCA), 80
American Juvenile Arthritis Organization (AJAO), 53
American Liver Foundation (ALF), 43
American Lung Association, 63
American Lupus Society, 46

American Medical Association (AMA), 82
American Medical Society on Alcoholism and Other Drug Dependencies, 66
American Mental Health Fund, 47
American Montessori Society, 14
American Narcolepsy Association, 58
American Nurses Association (ANA), 82
American Occupational Medical Association (AOMA), 79
American Occupational Therapy Association, Inc. (AOTA), 74, 82
American Orthopsychiatric Association, 48
American Parkinsons Disease Association (APDA), 58
American Physical Therapy Association (APTA), 74, 82
American Porphyria Foundation, 52
American Psychological Association (APA), 82
American Public Health Association (APHA), 27, 76, 83
American Public Welfare Association, 77
American School Health Association, 21
American Society for Deaf Children (ASDC), 30
American Society for Prophylaxis in Obstetrics (ASPO/LAMAZE), 2
American Society of Dentistry for Children (ASDC), 14
American Society of Human Genetics (ASHG), 28, 83
American Speech-Language-Hearing Association (ASHA), 30
American Tinnitus Association, 31
American Trauma Society, 10
Amyotrophic Lateral Sclerosis Association, 61
Angelman Research Group, 55
Arthritis Foundation,53
Association for Brain Tumor Research (ABTR), 32
Association for Childhood Education International (ACEI), 14
Association for Children and Adults with Learning Disabilities, Inc. (ACLD), 40
Association for Children with Down Syndrome, Inc. (ACDS), 34
Association for Glycogen Storage Disease, 50
Association for Macular Diseases, Inc., 69
Association for Recognizing the Life of Stillborns (ARLS), 4
Association for Retarded Citizens of the United States (ARC), 40
Association for the Advancement of Health Education, 79
Association for the Care of Children's Health (ACCH), 71
Association for Voluntary Surgical Contraception, 25
Association of Asian/Pacific Community Health Organizations (AAPCHO), 76
Association of Birth Defect Children (ABDC), 29
Association of Childbirth Assistants, 5
Association of Cytogenetic Technologists (ACT), 28
Association of Junior Leagues, 19
Association of Maternal and Child Health Programs (AMCHP), 80
Association of Medical School Pediatric Department Chairmen, 16
Association of Neuro-Metabolic Disorders, 51
Association of SIDS Program Professionals, 8
Association of State and Territorial Health Officials (ASTHO), 27, 76
Association of State and Territorial Public Health Nutrition Directors (ASTPHND), 27
Association of Teachers of Maternal and Child Health (ATMCH), 76
Asthma and Allergy Foundation of America, 63
Autism Society of America, 38
AVENUES (National Support Group for Arthrogryposis Multiplex Congenital), 53
Batten's Disease Support and Research Association, 56

Bay Area Self-Help Clearinghouse (California), 88
Benign Essential Blepharospasm Research Foundation, Inc., 61
Blind Children's Fund, 67
Boston Self-Help Center, 90
Brooklyn Self-Help Clearinghouse, 91
California Self-Help Center, 88
CAMAC, Inc., 98
Canadian Association for Williams Syndrome (CAWS), 52
Canadian Cancer Society, 31
Canadian Cerebral Palsy Association, 38
Canadian Hemophilia Society, 44
Candlelighters Childhood Cancer Foundation, 32
CAPC Self-Help Clearinghouse (New York), 91
Cattaraugus County Self-Help Clearinghouse (New York), 92
Celiac Sprue Association/United States of America, Inc. (CSA/USA), 42
Center for Hyperactive Child Information, Inc. (CHCI), 39
Center for Population Options (CPO), 19
Center for Science in the Public Interest (CSPI), 27
Center for Youth Services, 18
Cesarean Prevention Movement (CPM), 2
Cesareans Support, Education, and Concern (C/SEC), 2
Child Care Action Campaign, 13
Child Trends, Inc., 18
Child Welfare League of America, Inc. (CWLA), 12
Childbirth Education Foundation, 1
Children in Hospitals, Inc., 71
Children's Brain Diseases Foundation, 56
Children's Defense Fund (CDF),12, 19
Children's Foundation, 13
Children's Hospice International, 72
Children's Liver Foundation, Inc. (CLF), 43
Chronic Fatigue Immune Dysfunction Society, 46
Cleft Palate Parents' Council, 37
CMT International, Inc., 61
Coalition on Sexuality and Disability, 75
Committee for Responsible Genetics (CRG), 28
Compassionate Friends, Inc., 5
Concerned United Birth Parents (CUB), 11
Connecticut Self-Help/ Mutual Support Network, 89
Consumer Federation of America, 10
Cooley's Anemia Foundation, Inc., 45
Cornelia de Lange Syndrome (CdLS) Foundation, Inc., 39
Council for Exceptional Children (CEC), 75
Council of Chief State School Officers, 21
Council of Childbirth Education Specialists, 2
Council of Social Work Education (CSWE), 83
Council of State Administrators of Vocational Rehabilitation, 74
Council on Cardiovascular Disease in the Young, 33
Couple to Couple League International, 25
Cystic Fibrosis Foundation, 49
Cystinosis Foundation, Inc., 49
Dallas Self-Help Clearinghouse (Texas), 96
Deaf Children's Society of British Columbia, 30

Depression and Related Affective Disorders Association, Inc. (DRADA), 48
DES Action USA, 25
Donors' Offspring, 6
Dutchess County Self-Help Clearinghouse (New York), 92
Dysautonomia Foundation, Inc., 49
Dystonia Medical Research Foundation (DMRF), 61
Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.), 65
Ecumenial Child Care Network, 13
Education Commission of the States, 21
Ehlers-Danlos National Foundation (EDNF), 35
Emergency Nurses Association (ENA), 10, 83
Endometriosis Association, 26
Epilepsy Foundation of America (EFA), 56
Erie County Self-Help Clearinghouse (New York), 92
FACES — The National Association for the Craniofacially Handicapped, 36
Familial Polyposis Registry, 32
Families of S.M.A., 62
Family Life Education Council of Calgary, 98
Family Resource Coalition, 15
Fanconi Anemia Support Group, 43
Federation for Children with Special Needs, 72
5p- Society, 33
Foundation for Children with AIDS, 47
Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.), 65
Foundation for the Study of Wilson's Disease, Inc., 53
Fragile X Foundation, 34
Fragile X Support, Inc., 34
Franklin County Self-Help Clearinghouse (New York), 92
Freeman- Sheldon Parent Support Group, 54
Friedrich's Ataxia Group in America, Inc. (FAGA), 55
Fulton County Self-Help Clearinghouse (New York), 92
Future Homemakers of America, 21
G.I. Polyposis and Colon Cancer Registry, 32
Gluten Intolerance Group of North America (GIG), 42
Greene County Self-Help Clearinghouse (New York), 92
Guillain-Barré Syndrome Support Group International, 56
Haitian Self-Help Group Program, 90
Health and Human Services Outreach (Wisconsin), 97
Healthy Children Program, 21
Healthy Mothers, Healthy Babies National Coalition, 1
Helen Keller National Center for Deaf- Blind Youths and Adults, 68
Hemochromatosis Research Foundation, Inc., 44
Hereditary Disease Foundation, 57
Hereditary Hemorrhagic Telangiectasia Foundation, Inc. (HHT), 44
Herkimer County Self-Help Clearinghouse (New York), 93
Histiocytosis-X Association of America, Inc., 45
Human Growth Foundation (HGF), 64
Huntington Society of Canada, 57
Huntington's Disease Society of America, Inc. (HDSA), 57
I.V.H. (Intraventricular Hemorrhage) Parents, 8
Immune Deficiency Foundation, 46
Informed Homebirth/Informed Birth and Parenting, 1
Injury Prevention Center, 10

Institute on Black Chemical Abuse (IBCA), 66
Intergovernmental Health Policy Project, 78
International Association of Parents and Professionals for Safe Alternatives in Childbirth (NAPSAC, International), 2
International Childbirth Education Association (ICEA), 3
International Council of Guilds for Infant Survival, 8
International F.O.P. Association, Inc., 36
International Joseph Diseases Foundation, Inc. (IJDF), 58
International Lactation Consultant Association (ILCA), 7
International Rett Syndrome Association, Inc. (IRSA), 59
International Society of Nurses in Genetics, 28
Interstitial Cystitis Association, 43
Intestinal Multiple Polyposis and Colorectal Cancer (IMPACC), 32
Iron Overload Diseases Association, Inc. (IOD), 44
Joseph P. Kennedy, Jr. Foundation, 19, 40
Juvenile Diabetes Foundation International, 49
K-T Support Group, 39
La Leche League International, Inc., 7
Laurence-Moon-Biedl Syndrome (LMBS) Network, 39
Let's Face It, 37
Leukemia Society of America, Inc., 33
Little People of America, Inc. (LPA), 64
Long Island Self-Help Clearinghouse (New York), 93
Lowe's Syndrome Association, Inc., 50
Lupus Foundation of America (LFA), 46
Make Today Count, Inc., 72
Make-a-Wish Foundation of America, 72
Malignant Hyperthermia Association of the United States (MHAUS), 51
Maple Syrup Urine Disease (MSUD) Family Support Group, 51
March of Dimes Birth Defects Foundation, 6, 8, 19, 29
Massachusetts Clearinghouse of Mutual Support Groups, 90
Maternity Center Association (MCA), 1
McManus Health Policy, Inc., 78
Mental Health Association of Contra Costa (California), 89
Mental Retardation Association of America, Inc. (MRAA), 40
Merced County Self-Help Clearinghouse (California), 88
Michigan Protection and Advocacy Service, 90
Michigan Self-Help Clearinghouse, 90
Midland Area Support Group Network, 96
Midwives Alliance of North America (MANA), 6, 83
Minnesota Mutual Help Resource Center, 90
ML (Mucolipidosis) IV Foundation, 51
Monroe County Self-Help Clearinghouse (New York), 93
Montgomery County Enablers Advocating for New Support (MEANS) (New York), 93
Mothers of Asthmatics, Inc., 63
Mothers Without Custody, 15
Muscular Dystrophy Association (MDA), 62
Mutual Aid Self-Help Association (MASHA) (Wisconsin), 97
Myasthenia Gravis Foundation, 62
Myoclonus Families United, 62
NAACOG: The Organization For Obstetric, Gynecologic, and Neonatal Nurses, 1, 26, 85
National Academy for Child Development, 15
National Adoption Center, 11

National Alliance of Breast Cancer Organizations (NABCO), 32
National Alopecia Areata Foundation (NAAF), 64
National Apostolate with Mentally Retarded Persons (NAMRP), 40
National Association for Children of Alcoholics (NACOA), 66
National Association for Down Syndrome (NADS), 34
National Association for Family Day Care, 13
National Association for Hearing and Speech Action (NAHSA), 31
National Association for Home Care (NAHC), 72
National Association for Parents of the Visually Impaired (NAPVI), 68
National Association for Perinatal Addiction Research and Education (NAPARE), 66
National Association for Public Health Policy (NAPHP), 78
National Association for PXE (Pseudoxanthoma Elasticum), 36
National Association for Sickle Cell Disease, Inc. (NASCD), 45
National Association for the Dually Diagnosed (NADD), 41, 48
National Association for the Education of Young Children (NAEYC), 15
National Association for Visually Handicapped, 68
National Association of Anorexia Nervosa and Associated Disorders, Inc. (ANAD), 42
National Association of Childbearing Centers, 2
National Association of Childbirth Education (NACE), 3
National Association of Children's Hospitals and Related Institutions (NACHRI), 16, 72
National Association of Community Health Centers, Inc. (NACHC), 76
National Association of Counties, 77
National Association of County Health Officials, 77
National Association of Developmental Disabilities Councils, 38
National Association of EMS (Emergency Medical Services) Physicians, 10, 83
National Association of Native American Children of Alcoholics (NANACA), 66
National Association of Patients on Hemodialysis and Transplantation, Inc. (NAPHT), 47
National Association of Pediatric Nurse Associates and Practitioners (NAPNAP), 16, 22, 84
National Association of Radiation Survivors (NARS), 70
National Association of School Nurses, Inc., 22
National Association of Social Workers, Inc. (NASW), 84
National Association of State Alcohol and Drug Abuse Directors (NASADAD), 66
National Association of State Boards of Education, 22
National Association of State Directors of Special Education (NASDSE), 75
National Association of State EMS Directors, 11
National Association of State Mental Retardation Program Directors, 41
National Association of State School Nurse Consultants, 22
National Association of the Deaf (NAD), 30
National Ataxia Foundation, 56
National Black Nurses' Association, 84
National Black Women's Health Project, 24
National Cancer Care Foundation (NCCF), 31
National Center for Clinical Infant Programs (NCCIP), 7
National Center for Education in Maternal and Child Health (NCEMCH), 80
National Center for Health Education (NCHE), 79
National Center for Law and the Deaf, 30
National Center for Missing and Exploited Children, 12
National Center for Social Policy and Practice, 78
National Center for the Prevention of Sudden Infant Death Syndrome (NCPSIDS), 8
National Center for Youth Law, 18
National Center for Youth With Disabilities, 70
National Cleft Palate Association (NCPA), 37
National Coalition Against Domestic Violence, 24

National Coalition of Hispanic Mental Health and Human Services Organization (COSSHMO), 84
National Coalition to Prevent Childhood Injury, 11
National Commission to Prevent Infant Mortality, 7
National Committee for Adoption, 11
National Committee for Prevention of Child Abuse (NCPCA), 12
National Conference of State Legislatures, 78
National Congenital Port Wine Stain Foundation, 64
National Congress of Parents and Teachers (National PTA), 15, 22
National Council on Alcoholism, Inc., 67
National Council on Family Relations (NCFR), 16
National Council on Patient Information and Education (NCPIE), 79
National Down Syndrome Congress (NDSC), 34
National Down Syndrome Society (NDSS), 34
National Easter Seal Society, 74
National Education Association (NEA), 15, 22
National Emergency Medicine Association, 11
National Family Planning and Reproductive Health Association (NFPRHA), Inc., 25
National Foundation for Ectodermal Dysplasias (NFED), 64
National Foundation for Facial Reconstruction, 36
National Foundation for Ileitis and Colitis, Inc. (NFIC), 43
National Foundation for Jewish Genetic Diseases, Inc. (NFJGD), 29
National Foundation for Peroneal Muscular Atrophy, 61
National Foundation of Dentistry for the Handicapped (NFDH), 14, 71
National Gaucher Foundation, Inc., 50
National Governor's Association, 78
National Head Injury Foundation, Inc., 57
National Head Start Association, 15
National Hemophilia Foundation (NHF), 44
National Hospice Organization (NHO), 72
National Hydrocephalus Foundation (NHF), 57
National Indian Health Board, 80
National Information Center for Children and Youth with Handicaps (NICHCY), 75
National Information Center for Health Related Services, 70
National Information Center on Deafness, 30
National Institute for Adolescent Pregnancy and Family Services, 19
National Kidney Foundation, Inc., 47
National League for Nursing (NLN), 84
National League of Cities, 77
National Marfan Foundation (NMF), 36
National Maternal and Child Health Resource Center, 73, 80
National Medical Association (NMA), 84
National Mental Health Association (NMHA), 48
National Migrant Referral Project, Inc., 77
National MPS Society, 51
National Multiple Sclerosis Society, 62
National Myoclonus Foundation, 62
National Network of Runaway and Youth Services, Inc., 18
National Network to Prevent Birth Defects, 6
National Neurofibromatosis Foundation, Inc., 58
National Organization for Albinism and Hypopigmentation (NOAH), 48
National Organization for Rare Disorders Inc. (NORD), 29, 71
National Organization of Circumcision Information Resource Centers (NO-CIRC), 4
National Organization of Mothers of Twins Clubs, Inc. (NOMOTC), 3

National Organization on Adolescent Pregnancy and Parenting, Inc. (NOAPP), 19
National Organization on Disability (NOD), 71
National Parent Chain (Coalition for Handicapped Americans Information Network), 73
National Parkinson Foundation, Inc. (NPF), 58
National Perinatal Association (NPA), 4
National Perinatal Bereavement Alliance (NPBA), 5
National Perinatal Information Center, 4
National Recreation and Park Association, 73
National Rehabilitation Association, 74
National Rehabilitation Information Center (NARIC), 74
National Resource Center for Children in Poverty, 12
National Resource Institute on Children and Youth With Handicaps (NRICH), 70
National Reye's Syndrome Foundation, 17
National Rural Health Care Association (NRHA), 77
National Safety Council, 11
National School Boards Association, 22
National School Health Education Committee, 23
National School Volunteer Program, 23
National Scoliosis Foundation, Inc., 54
National Self-Help Clearinghouse, 88
National Society of Genetic Counselors (NSGC), 28, 84
National Society to Prevent Blindness, 68
National Spasmodic Torticollis Association, 59
National Sudden Infant Death Syndrome Clearinghouse, 9
National Sudden Infant Death Syndrome Foundation, Inc., 9
National Tay-Sachs and Allied Disease Association (NTSAD), 52
National Therapeutic Recreation Society, 73
National Tuberous Sclerosis Association (NTSA), 60
National Urban League, Inc., 20
National Wellness Association, 79
National Women's Health Network, 24
New Futures School, 23
New Jersey Self-Help Clearinghouse, 91
New York City Self-Help Clearinghouse, Inc., 93
New York State Self-Help Clearinghouse, 93
Niagara County Self-Help Clearinghouse (New York), 93
Northwest Regional Self-Help Clearinghouse (Oregon), 95
Office of Family Poicy and Support, Assistant Secretary of Defense, Force Management and Personnel, 78
Oneida County Self-Help Clearinghouse (New York), 94
Onondaga County Self-Help Clearinghouse (New York), 94
Organic Acidemia Association, Inc., 52
Orton Dyslexia Society (ODS), 40
Osteogenesis Imperfecta Foundation, Inc. (OIF), 54
Osteogenesis Imperfecta-National Capital Area (OI-NCA), 54
Oswego County Self-Help Clearinghouse (New York), 94
Overlook Mental Health Center (Tennessee), 96
Paget's Disease Foundation, Inc., 54
Parent Care, Inc., 8
Parentele, 73
Parents and Cataract Kids (PACK), 68
Parents of Galactosemic Children, Inc., 50
Parkinson's Disease Foundation, Inc. (PDF), 59

PEP (Parkinson's Educational Program) USA, 59
Planned Parenthood Federation of America, Inc., 25
(PKR) Polycystic Kidney Research Foundation, 47
Positive Pregnancy and Parenting Fitness, 4
Prader-Willi Syndrome Association (PWSA), 35
Pregnancy and Infant Loss Center (PILC), 5
Prescription Parents, Inc., 37
Progeria International Registry, 41
Public Health Foundation, 76
Reach Out to the Parents of an Unknown Child, Inc., 5
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), 59
Refugee Health Issues Center, 77
Rehabilitation International, 75
Rensselaer County Self-Help Clearinghouse (New York), 94
Resolve Through Sharing, 5
Resolve, Inc., 26
Riverwood Community Mental Health Center (Michigan), 90
R.P. Foundation Fighting Blindness, 69
Robert Wood Johnson School Based Adolescent Health Care Program, 23
Rockland County Self-Help Clearinghouse and Information Center (New York), 94
Rubinstein-Taybi Syndrome (RTS) Parent Group, 41
Sacramento Self-Help Clearinghouse (California), 89
Saint Lawrence County Self-Help Clearinghouse, Inc. (New York), 94
Saskatchewan Self-Help Development Unit, 98
Schenectady County Self-Help Clearinghouse (New York), 95
School Health Programs, 23
Schuyler/Chemung Self-Help Clearinghouse (New York), 95
Scoliosis Association, Inc., 54
Self-Help Center (Illinois), 89
Self-Help Clearinghouse for Metropolitan Toronto, 98
Self-Help Clearinghouse of Greater Washington, 97
Self-Help for Hard of Hearing People (SHHH), 30
Self-Help Group Network of the Pittsburgh Area, 95
Self-Help Information Services (Nebraska), 91
Self-Help Network (Kansas), 89
Sex Information and Education Council of the United States (SIECUS), 26
SHARE (Source of Help in Airing and Resolving Experiences), 5
Share and Care, 39
S.H.I.N.E. (Self-Help Information Network Exchange, Pennsylvania), 96
Sibling Information Network, 73
Sjogren's Syndrome Foundation, Inc., 46
SKIP (Sick Kids need Involved People, Inc.), 73
Smith-Lemli-Opitz Syndrome Support Group, 41
Society for Adolescent Medicine (SAM), 18, 85
Society for Nutrition Education, 27
Solvent Abuse Foundation for Education (SAFE), 67
Speaking for Ourselves (S4OS), 48
Special Olympics International, 73
Spina Bifida Association of America (SBAA), 60
Stepfamily Association of America, Inc., 16
State Medical Directors' Association, 77
Stop Teenage Addiction to Tobacco (STAT), 67
Sturge-Weber Foundation, 60

Support Center for School-Based Clinics, 18
Support Group Clearinghouse (Missouri), 91
Support Group for Monosomy 9P, 35
Support Organization for Trisomy 18/13 and Other Related Disorders (S.O.F.T. 18/13), 35
Tarrant County Self-Help Clearinghouse (Texas), 96
TASH: The Association for Persons with Severe Handicaps, 71
Teratology Society, 6
Thalassemic Action Group, 45
Thrombocytepenia Absetn Radius Association (TARSA), 45
Tomkins County Support Group Clearinghouse, 95
Toughlove, 20
Tourette Syndrome Association, Inc. (TSA), 60
Tri-County Clearinghouse (Placer, Yolo, Sacramento), 89
Triplet Connection (TC), 3
Tuberous Sclerosis Association of America, Inc. (TSAA), 60
Turner's Syndrome Society, 35
Twinline, 3
Twins Foundation, 3
United Cerebral Palsy Association (UCPA)/UCP Research and Educational Foundation, 38
United Leukodystrophy Foundation, Inc. (ULF), 50
United Scleroderma Foundation, Inc. (USF), 65
Vermont Self-Help Clearinghouse, 97
Very Special Arts, 74
Vision Foundation, Inc., 68
Westchester Self-Help Clearinghouse, 95
Williams Syndrome Association (WSA), 52
Wilson's Disease Association, 53
Winnipeg Self-Help Resource Center, 98
Women's International Network (WIN), 24
Women's Occupational Health Resource Center (WOHRC), 24
Xeroderma Pigmentosum Registry, 65
Youth Suicide National Center, 20
Zain Hansen M.P.S. Foundation, 51